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Theme 1: Planning and Reform

1.1 State Plans

1995-1997 Developmental Disabilities Three-Year State Plan Fiscal Years 1995 - 1997 (September 1996).

1991-1994 State of Minnesota Developmental Disabilities Three-Year Plan, October 1, 1991 to September 30, 1994: Interdependence, Inclusion, and Contribution (March, 1992).

1989-1991 Two-Year Transitional Plan, State of Minnesota Developmental Disabilities: October 1, 1989 - September 30, 1991: Accountability (January 1990).

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1976-1979 1977 Minnesota Developmental Disabilities State Plan (Volumes 1 and 2) (1976).

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Minnesotans Speak Out! (1992).

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Americans with Disabilities, Agenda for Change (1991).

A New Way of Thinking (1987).

Mandate for Action: Recommendations of the Governor's Mental Health Commission (February 3, 1986).

Testimony of Colleen Wieck: Needed Changes in the Medicaid System, and Support for the Community and Family Living Amendments (1986).

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Fiscal Disincentives in the Service System for People with Developmental Disabilities (June 1983).

Developmental Disabilities and Public Policy, A Review for Policymakers (January 1983).

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CAIR — Community Alternatives and Institutional Reform, Planning Alternatives for the Developmentally Disabled Individual (January 1975).

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Action Speaks Louder... A Plan for Minnesota's Mentally Retarded (A Pamphlet Summary of the Plan (1964).

Report to the Governor. A Comprehensive Plan to Combat Mental Retardation in the State of Minnesota. Volume 1. A Philosophy of Progress. Prepared by the Minnesota Mental Retardation Planning Council (April 1966).

Report to the Governor. A Comprehensive Plan to Combat Mental Retardation in the State of Minnesota. Volume II. Array of Services: The Facilities Construction Plan. Prepared by the Minnesota Mental Retardation Planning Council (April 1966).

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PAS No.1 Taxonomy of Issues Surrounding Implementation of the Welsch vs. Noot Consent Decree (March 31, 1981).

PAS No. 2 The Size of Community Residential Facilities: Current Guidelines and Implications for Planning (April 10, 1981; revised August 1981).

PAS No. 3 Interagency Cooperation: The Underlying Concepts of Trust, Incentives, Barriers, and Forms of Linkage (April 14, 1981; revised 8/24/81).

PAS No. 4 Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems (September 1, 1981).

PAS No. 5 Admissions/Readmissions to State Hospitals September 1, 1980 to May 31, 1981: The Behavior Problem Issue (August 31, 1981).

PAS No. 6 The Financial Status of Minnesota Developmental Achievement

Centers: 1980 -1982 (January 11, 1982).

PAS No. 7 The Program Status of Minnesota Developmental Achievement Centers: 1980 -1982 (January 18, 1982).

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PAS No. 9 Summary of Issues, Programs and Clients in Minnesota Developmental Achievement Centers: 1980 - 1982 (February 10, 1982).

PAS No. 10 An Update to Policy Analysis Series No. 5, Admissions/Readmissions to State Hospitals June 1, 1980 to December 31, 1982: The Behavior Problem Issue (April 9, 1982).

PAS No. 11 An Analysis of Minnesota Property Values of Community Intermediate Care Facilities for Mentally Retarded (ICF-MRs) (July 1, 1982).

PAS No. 12 Analysis of Nonformal Training for Personnel Working in the Field of Developmental Disabilities in Minnesota: 1981 - 1982 (January 3, 1983).

PAS No. 13 A Survey of Formal Training Programs in Developmental Disabilities in Postsecondary Schools in Minnesota and Adjacent States (January 3, 1983).

PAS No. 14 Training Needs as Perceived by Residential and Day Program Administrators and Staff (April 13, 1983).

PAS No. 15 An Update to Policy Analysis Series No. 4: Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems: 1980 (March 14, 1983).

PAS No. 16 A Statewide Summary of Sheltered Employment Programs (April 19, 1983).

PAS No. 17 An Update to Policy Analysis Series No. 6 through 9 - The Financial, Client and Program Status of Minnesota Developmental Achievement Centers: 1982 (March 28, 1983).

- PAS No. 18 The Minnesota Family Subsidy Program: Its Effects on Families with a Developmentally Disabled Child (May 2, 1983).
- PAS No. 19 An Update to Policy Analysis Series No. 4 and 15: Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems: 1981 (August 15, 1983).
- PAS No. 20 Respite Care: A Supportive and Preventive Service for Families (October 18, 1983).
- PAS No. 21 Summary and Analysis of Minnesota Developmental Disabilities Respite Care Demonstration Projects (Federal Fiscal Years 1981-1983) (October 24, 1983).
- PAS No. 22 Improving the Quality of Life for People with Disabilities: Potential Uses of Technology (April 1984).
- PAS No. 23 An Update to Policy Analysis Series No. 6 - 9 and 17: The Financial, Client and Program Status of Minnesota Developmental Achievement Centers: 1980 -1984 (January 2, 1987).
- PAS No. 24 Minnesota Case Management Study/Executive Summary (February 1988).
- PAS No. 25 Minnesota Developmental Achievement Centers: An Update to Welsch Policy Analysis Papers No. 6 - 9, 17, and 23 (February 1988).
- PAS No. 26 Supported Employment: Review of Literature (March 31, 1989).
- PAS No. 27 Supported Employment: Review of Grant Recipients and 1986 DAC Data (March 31, 1989).
- PAS No. 28 Minnesota Developmental Achievement Centers: 1987 Survey Results (May 1989).
- PAS No. 29 Minnesota Day Training and Habilitation Services: 1988 Survey Results (December 1989).
- PAS No. 30 Financing of Supported Employment for Persons with Severe Disabilities (January 1990).

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PAS No. 2 Minnesota State Hospital Energy Use and Cost (January 31, 1985).

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PAS No. 5 Public Opinions about State Hospitals (January 31, 1985).

PAS No. 6 Residents/Patients in Minnesota State Hospitals (January 13, 1985).

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PAS No. 8 Options and Recommendations for the Minnesota State Hospital System (January 31, 1985).

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Study of Minnesota School for the Deaf and Blind. Report Submitted to Governor Rudy Perpich by Minnesota State Planning Agency (1984-1986).

- Evaluation of the Minnesota School for the Deaf and The Minnesota Braille and Sight-Saving School. Program Evaluation Division, Office of the Legislative Auditor (January 4, 1984).
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Students, Families, and Local Schools. Minnesota State Planning Agency (February 8, 1985).

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- Concise Summary of Recommendations. Fred Schroeder and David Ticchi (November 27, 1985).
- The Academic and Residential Programs at the Minnesota State Academy for the Deaf. Frank Zieziula, Ph.D., James Collins, Ph.D., and Gerald Nelson (November 1985).
- Financial Structure of the Minnesota Academy for the Deaf and Minnesota Academy for the Blind. Minnesota Department of Finance (January 1986).
- Working Paper on Governance Options for the Minnesota Academy for the Deaf and Minnesota Academy for the Blind. Management Analysis Division of the Minnesota Department of Administration (January 1986).
- Working Paper on Organizational Options for the Minnesota Academy for the Deaf and Minnesota Academy for the Blind. Management Analysis Division of the Minnesota Department of Administration (January 1986).
- Letter from the Minnesota State Board of Education, Regarding State Board of Education Response on the Consultant Reports Relating to the Faribault Residential Academies. Ruth Myers, President (January 7, 1986).

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Shaping Case Management in Minnesota -- in theory, reality and practice. Minnesota Governor's Planning Council on Developmental Disabilities (January 1991).

Case Management: Historical, Current and Future Perspectives. Edited by Mary Hubbard Linz, Patricia McAnally, and Colleen Wieck. Cambridge MA: Brookline Books (1989).

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Family Support -- A Check for Quality. The Family Support Project, The Arc National Headquarters (January 1993).

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Final Report, Legislative Task Force on Employment for People Who Are Disabled. Prepared for Minnesota State Planning Agency. Prepared by Mediation Center, St. Paul, Minnesota (February 1, 1988).

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How to Position People with Severe Disabilities. Joan S. Bergman, Ph.D. Produced by the Minnesota Governor's Planning Council on Developmental Disabilities (undated - 1989).

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1.11 Public Information

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2.1 Self Determination and Person Centered Planning

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Making Futures Happen: A Manual for Facilitators of Personal Futures Planning. Written by Beth Mount. Produced by Kay Zwernik. The Metropolitan Council (1992, reprinted August 1994).

Listen, Lady, This is My Life: A Book of Stories about Personal Futures Planning in Minnesota. Angela Novak Amado and Patricia L. Lyon. Human Services Research and Development Center (1992).

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Parent Advocacy -- Changing Expectations/Planning for the Future. An Advocacy Training Manual. Legal Advocacy for Developmentally Disabled

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Community Residential Advocacy for Persons with Developmental Disabilities: Current Status and Future Development. Developmental Disabilities Planning Office, Minnesota State Planning Agency (April 1981).

2.3 Partners in Policymaking

Partners in Policymaking Restored Our Independence! Testimonial Letters (1995).

Partners in Policymaking — Curriculum Part One: Highlights. Minnesota Governor's Planning Council on Developmental Disabilities (May 1993; revised January 1995).

Partners in Policymaking -- Coordinator's Handbook . Prepared by Kathie Snow in Consultation with Jopie Smith and Colleen Wieck (October 1995).

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Position Statements for the Minnesota Governor's Council on Developmental Disabilities (June 7, 1995).

Testimony to the Senate Subcommittee on Disability Policy, Hearing Regarding Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act, June 29, 1993. Submitted by Sue Swenson.

Information about the Minnesota Governor's Planning Council on Developmental Disabilities (October 1991).

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Minnesota Governor's Planning Council on Developmental Disabilities Philosophy and Mission (revised December 1979).

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Grant Policy — Minnesota Governor's Planning Council on Developmental Disabilities (1992).

Summary - McKnight Foundation. Governor's Planning Council on Developmental Disabilities (April 1988).

Summary — McKnight Foundation Developmental Disabilities Program. The Minnesota State Planning Agency, January 1982 - June 1983. Minnesota State Planning Agency (1983).

Report on Regional Site Visits F.Y. 1980. Developmental Disabilities Planning Office (October 1980).

Developmental Disabilities Service Grants, 1972 - 1976. A Follow-Up Study. Developmental Disabilities, Minnesota State Planning Agency (September 1978).

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Person-Centered Planning and Community Action Approaches for Transition to Employment. Concept Paper and Proposals for Possible Pilot Projects. Prepared by Human Services Research & Development Center for the Minnesota Governor's Council on Developmental Disabilities (May 31, 1995).

The Career Planning Process: A First Step for Supported Employment. A report compiled by Kaposia, inc. (1990).

It's Working — Minnesota Supported Employment Project (June 1, 1988).

Reports by Employment Related Activities Grant Recipients. Memo to Members of the Governor's Planning Council on Developmental Disabilities (June 30, 1986).

o The Voucher System

Dakota County Account Management Program. Humphrey Innovation and Organization Project (June 1, 1992).

Dakota County Account Management Project. (Evaluation of Year 2) (undated).

o Youth Leadership, Friendships, and Volunteers

Leadership for Empowerment Program - Serving Junior High Youth with and without Developmental Disabilities. Prepared by the Leadership for Empowerment Program, YMCA of Metropolitan Minneapolis, Ridgedale Branch (1995).

SCOLA Leisure Activity Fun Guide. (Includes Fun Futures, Community Recreation and Children with Developmental Disabilities). SCOLA of Arc

Ramsey County (April 1991).

Friends, A Manual for Connecting Persons with Disabilities and Community Members. Angela Novak Amado, Fran Conklin, and Jane Wells. Human Services Research & Development Center, 1989-90 Friends Project (1989; reprinted 1991).

Person to Person: Volunteer Recruitment and Training Guidebook. Written by Jackie Sinykin & Sue Vineyard, under contract with the Minnesota Department of Human Services (April 1989).

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McKnight Problem-Solving Grant: Supplemental Security Income (SSI) Working Paper. Arrowhead Regional Development Commission (July 19, 1984).

Potential Funding Sources for Advocacy Programs. Compiled by Developmental Disabilities Protection and Advocacy System; Developmental Disabilities Planning Office, Minnesota State Planning Agency (February 1979).

3.3 General Information

Minnesota Governor's Planning Council on Developmental Disabilities Publications (May 1995).

Glossary of Acronyms and Terms Related to Developmental Disabilities. Governor's Planning Council on Developmental Disabilities (March 1989).

Trend Reports. State Planning Agency, Developmental Disabilities.
Minnesota State Planning Agency (December 1987).

A Writer's Reference to Developmental Disabilities (January 1980).

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Chronology of Minnesota and National Events According to DD Newsletters (March 1995).

DD Information Exchange (October 1981 to September 1990).

Futurity (November 1990 to June 1995).

Theme 1: Planning and Reform Documents

Introduction to Planning and Reform Documents

According to the Developmental Disabilities Assistance and Bill of Rights Act of 1996 (P.L. 104-183), each state Developmental Disabilities Council is

- to promote through systemic change, capacity building, and advocacy activities,
- the development of a consumer and family-centered, comprehensive systems, and a coordinated array of culturally competent services, supports and other assistance
- designed to achieve independence, productivity, and integration and inclusion into the community for individuals with developmental disabilities.

P.L. 104-183, and its predecessors, also make each state Council responsible for preparing a three-year state plan describing the quality, extent, and scope of needed services being provided or to be provided to persons with developmental disabilities; to monitor and evaluate the implementation of the state plan; and to review state service plans for persons with developmental disabilities.

These two mandates have involved the Minnesota Governor's Council on Developmental Disabilities in the development of a considerable number of documents. Some, like State Plans, have been primarily for the purposes of complying with Federal Law. Every three years, or more often as required from time to time, the Governor's Council on Developmental Disabilities has developed a plan for the next period.

In 1986, the Minnesota Governor's Council on Developmental Disabilities

was cited as one of ten exemplary human service planning agencies. One of the reasons for its selection was the fact that the Council demonstrated one of the distinctions between mere plan making and true strategic planning. According to Bill Benton in describing ten characteristics of exemplary planning:

Plan making is the process of preparing a document.
Planning is the process of translating vision into reality.

Planning attempts to make the future different that it otherwise might be.
Plan-making makes no difference at all.

The Minnesota Governor's Council on Developmental Disabilities has a history of trying to make a difference, to shape the future, rather than simply be shaped by it.

The documents in this section chronicle plan-making, planning and reform efforts over three decades.

Section 1.1 State Plans presents the State Plans required by Federal Law for the 22 year period 1975 to 1997. The bulk of these plans simply document the status of services and the activities of State agencies. On the proactive side, they provide the context for the Governor's Council on Developmental Disabilities to identify a state priority for a three year period. The priority provides a focus for grant activities during that period. Section 3.2 presents an overview of these grants over the years. The State Plan also describes where funds for developmental disabilities services were allocated at a particular point in time.

The rest of the sections under this theme are more about planning than plan-making, changing law and policy, rather than complying with it.

Section 1.2 The Big Picture contains a series of documents intended to change the way policymakers see issues facing people with developmental disabilities and the ways that the system can respond to them. These documents are about paradigm shifts and major systemwide changes in public policy.

Section 1.3 and Section 1.4 The Policy Analysis Series relates to the Welsh Consent Decree and to Minnesota's State Hospitals. These documents were developed over a decade, but particularly in the first half of the 1980s. They address the major issues of deinstitutionalization and

the future of Minnesota's State Hospitals. In the words of the report on ten exemplary human service planning efforts —

The policy papers received both a great deal of use and a great deal of praise for being both scholarly and readable. They bridged the chasm that had previously existed between research and the policy process. (Urban Systems Research & Engineering, Inc. 1985: 3-28.)

Sections 1.5 to Section 1.11 Documents that address reform in specific areas — the Minnesota Academies for the Deaf and the Blind, technology, case management, family support, employment, training and staff development, and public information. Many of these documents were part of successful efforts to change policy and practice in Minnesota; other documents had nationwide impact.

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1.1 State Plans

Background/Context:

In the early 1970s, statewide planning for developmental disabilities services began to involve the creation of formal, written plans. Following the Presidential mandate for deinstitutionalization and in keeping with the National Developmental Disabilities Advisory Council priority, the Minnesota Developmental Disabilities Program received a grant under Public Law 91-517 to create a process for establishing community alternatives for individuals with developmentally disabilities.

The grant supported the Community Alternatives and Institutional Reform (CAIR) Project. The CAIR Report created a blueprint for the future, and focused on developing an individual-centered process for determining the needs of individuals as the basis for returning persons in state facilities to community settings.

Public Law 91-517 (Developmental Disabilities Services and Facilities Construction Act of 1971) also required States to develop state plans to describe how federal funds would be used to fill gaps in the existing service structure and expand services to those not receiving services. State plans continue to be required by the Developmental Disabilities Assistance and Bill of Rights Act of 1996 (Public Law 104-183), Part B, "Federal Assistance to State Developmental Disabilities Councils." Under this Act, federal funds are made available to states for the following purpose:

... to promote, through systemic change, capacity building, and advocacy activities...., the development of a consumer and family-centered, comprehensive system, and a coordinated array of culturally competent services, supports, and other assistance designed to achieve independence, productivity, and integration and inclusion into the community for individuals with developmental disabilities. [Sec. 121]

The plan, once approved by the Secretary of the Department of Health and Human Services, provides the basis upon which a state will participate in programs and activities under Title II, Part B of the Act.

Historically, these plans have been very long documents which present a

status report on services provided by state agencies; articulate the mission and mandate of the Governor's Council on Developmental Disabilities; identify the priorities, goals and objectives of the Council; and report on progress toward previous goals and objectives. While they have captured information about what was going on in the State at a given period of time, and where the Federal funds to the Council went, these plans are essentially compliance documents . While called "State Three Year Plans", they are not, in fact, real plans. They only describe the Council's plans and priorities. They have not been useful in shaping public policy in Minnesota. The Council developed a number of other strategies to effect State planning — for instance, the Policy Analysis Series related to the Welsch Consent Decree and the reform of the State Mental Hospital system; a series of policy briefing books for State legislators and others which have become "best sellers" across the United States.

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Overview of State Plans: 1975-1997

Developmental Disabilities Three-Year State Plan Fiscal Years 1995 - 1997 (September 1996).

State Priority: Leadership

Goals:

- Youth Leadership. To increase the inclusion of youth with developmental disabilities in leadership programs.
- Partners in Policymaking. To increase the number of citizen leaders by training adults with disabilities and family members to be culturally competent, knowledgeable about state-of-the-art services, skilled in educating public officials and in developing constructive/positive relationships with policymakers at all levels of government, and represent unserved/underserved counties.
- Advanced Leadership Training. To promote ongoing statewide participation of citizen leaders by offering advanced leadership

training opportunities in advocating for integrated and inclusive life opportunities.

- Public Awareness, Public Policy and Capacity Building. To increase the knowledge, improve the skills, and change the attitudes of the general public; to promote integration and inclusion, interdependence, productivity of, and contributions by individuals with developmental disabilities through public education and dissemination of publications.

Federal Priority: Employment

Goal: To increase employment opportunities for individuals with developmental disabilities by strengthening and improving the process of transition from school to adulthood through person centered planning, career planning, and systems change.

State of Minnesota Developmental Disabilities Three-Year Plan, October 1, 1991 to September 30, 1994: Interdependence, Inclusion, Contribution (March 1992).

State Priority: Leadership

Strategies:

- To develop local and statewide leadership (people with disabilities, families, youth, civic leaders, and citizens) through state-of-the-art training, skill, and competency-based curriculum, and real community-based experience.
- To organize and sustain new civic networks, coalitions, and alliances specifically to advance the full inclusion and economic independence of individuals with the most severe disabilities.
- To influence and change local, state and federal laws, policies, regulations, service delivery, civic and social values, and cultural images to:
 - Promote full democratic participation, personal enfranchisement, command of meaningful choices, and resources.
 - Eliminate deviancy-based segregation and exclusions, disincentives to the exercise of full participation in all our social institutions, and end the conditions that impose economic underdevelopment and impoverishment of people with disabilities.

Two-Year Transitional Plan, State of Minnesota Developmental Disabilities October 1, 1989 - September 30, 1991: Accountability (January 1990).

State Priority: Accountability.

Overall Goals:

- To increase accountability to individuals with developmental disabilities of all ages to improve independence, productivity, and integration into the community.
- To increase accountability to individuals with developmental disabilities of all ages by building community capacity to support individuals; and
- To increase accountability to individuals with developmental disabilities of all ages by changing state policies to be more responsive to individuals who are unserved or underserved.

State of Minnesota Developmental Disabilities Three-Year State Plan, 10/1/86 - 9/30/89 (1986).

State Priority: Case Management

Goal: By 1989, the efficiency, responsiveness, and measurable effectiveness of case management services for persons with developmental disabilities will increase.

State of Minnesota Developmental Disabilities, A Three Year Plan, 10/1/83 - 9/30/86 (1983).

State Priority: Day Services

Goal : To improve the quantity and quality of day services for people with developmental disabilities, especially those who have behavioral problems, are severely or profoundly retarded, or are not mentally retarded.

Developmental Disabilities Three Year State Plan, October 1, 1980 to September 30, 1983 (1980).

Priorities of Council :

- . To expand and improve the delivery of residential services in the least restrictive alternative.
- . To assure more/better coordinated service delivery to persons with

developmental disabilities by providing interagency coordination and technical assistance at the local level of service delivery.

Developmental Disabilities State Plan: An Update, Fiscal Year 1980 (1979).

Goals of the Council :

- Comprehensive Planning: To design and implement a uniform statewide service planning process...
- Advocacy: ... serve as an advocate for the improvement of the life quality and services for persons who are developmentally disabled ...
- Screening: To review the present status and make recommendations for developing a coordinated statewide sub-system in prevention, identification, diagnosis/assessment, intervention and follow-along services.
- Public Information: ... increase public awareness, information and education...
- Governmental Operations:... review and comment on major Federal and State plans, existing laws and proposed legislation, administrative rules and regulations in order to influence development of policies...
- Grant Review: ... continue to carry out grant review activities that involve people with developmental disabilities and their families, and developmental disabilities services and resources in Minnesota.

Minnesota Developmental Disabilities State Plan, F.Y. 1978 (1977).

Goals Ranked in Importance :

- Advocacy
- Comprehensive Planning, Governmental Operations
- Public Information
- Screening
- Evaluation
- Grant Review.

1977 Minnesota Developmental Disabilities State Plan (Volumes 1 and 2) (1976).

Task Groups and Goals Related to : Comprehensive planning (state and regional), public communication, advocacy, plan review and legislation, organization and management of regional planning, state organization and management, increased services, and special studies.

State of Minnesota State Plan Annual Revision FY 1976, July 1, 1975 to June 30, 1976 (Volume I and Volume II Appendices) (1975).

Short Range Goal:

- Compliance with Federal Goals: to reduce by one-third the institutional caseload for people with mental retardation and other developmental disabilities.

Additional Goals:

- Community Alternatives and Institutional Reform (CAIR), Regional Planning, Regional Administration and Service Delivery, Public Information/Education and Advocacy, and Program Monitoring and Evaluation.
-

Index of State Plans

- 1995-1997 Developmental Disabilities Three-Year State Plan Fiscal Years 1995 - 1997 (September 1996).
- 1991-1994 State of Minnesota Developmental Disabilities Three-Year Plan, October 1, 1991 to September 30, 1994: Interdependence, Inclusion, and Contribution (March 1992).
- 1989-1991 Two-Year Transitional Plan, State of Minnesota Developmental Disabilities: October 1, 1989 - September 30, 1991: Accountability (January 1990).
- 1986-1989 State of Minnesota, Developmental Disabilities Three-Year State Plan, 10/1/86 - 9/30/89 (1986).
- 1983-1986 State of Minnesota Developmental Disabilities, A Three Year Plan (10/1/83 - 9/30/86) (1983).
- 1980-1983 Developmental Disabilities Three Year State Plan, October 1, 1980 to September 30, 1983 (1980).
- 1979 Developmental Disabilities State Plan: An Update, Fiscal Year 1980 (1979).
- 1978-1979 Minnesota Developmental Disabilities State Plan, F.Y. 1978 (1977).
- 1976-1979 1977 Minnesota Developmental Disabilities State Plan (Volumes 1 and 2) (1976).
- 1975-1976 State of Minnesota State Plan Annual Revision FY 1976, July 1, 1975 to June 30, 1976 (Volume I and Volume II Appendices) (1975).

1.2 The Big Picture -- Paradigm Shifts and Agendas for Change

Before Federal Legislation (currently the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1996, P.L. 104-183) required the development of state plans, there were many efforts in Minnesota to identify issues affecting the lives of people with developmental disabilities and recommend action to address those issues and support individuals to be full and included members of Minnesota's communities. Thirty years of publications articulate agendas for change, suggest changes in the ways we think and act, and call on all levels of government to support change.

A Minnesota Mental Retardation Planning Council was appointed by Governor Rolvaag in 1964. In language that underscores the changes that have occurred in our thinking, the Governor charged the Council to develop a comprehensive plan to "combat mental retardation in Minnesota." That Council developed such a comprehensive plan.

A second wave of reform efforts began in 1974 with a Governor's Conference on Handicapped Persons. A Coalition of over 80 groups and organizations developed a set of recommendations for Governor Wendell Anderson. The Community Alternatives and Institutional Reform project was underway at the same time.

In the 1980s and continuing in the 1990s, the Minnesota Governor's Council on Developmental Disabilities developed a series of documents which have become nationally and internationally renowned for their efforts to lay out, in accessible ways, an agenda for change. These documents focused on the big picture — the ways we organize our thinking and actions in support of individuals with developmental disabilities and called for policy changes at the state and national level. The Minnesota Governor's Council on Developmental Disabilities provided national leadership for efforts such as Medicaid reform, family support legislation, and a new and responsive Rehabilitation Act.

Proceed to _

- _ The Agenda for Change — 1980 to today
- _ Early Reform Efforts

_ Index of The Big Picture Documents

1.2.1 The Agenda for Change — 1980 to today.

Minnesotans Speak Out! (1992).

On January 27, 1992, the Deputy Commissioner of the Department of Human Services appointed a study group to “review the current structure under which developmental disabilities services are provided and to review costs.” The study group decided to seek input from Minnesotans through a series of town meetings. Because of its long track record in town meetings and public input, the Governor’s Council on Developmental Disabilities conducted the meetings and prepared this report. The report summarizes the themes discussed at the town meetings and over the phone during a toll-free, call-in day. The report concludes with recommendations from the study group.

The themes discussed are:

- . We have a lot to be proud of, and much remains to be done!
- . Individualization
- . Staffing
- . Leadership and Bureaucracy
- . Inequity of Resources -- Inconsistency in the System
- . Community Programs and Supports.

This document is used frequently, though not by the people who commissioned it. The Governor’s Council on Developmental Disabilities uses it in speeches and slide shows related to the realities of the service delivery system in Minnesota and quality assurance issues.

1990 Report: "The heart of community is inclusion..." (1990).

This report was prepared to fulfill requirements of the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100-146). Federal Law required a survey of needs, an examination of eligibility, and a definition of unserved and underserved populations.

The 1990 Report provided a context to discuss three major issues:

- Eligibility issues which lead to the exclusion of individuals with developmental disabilities from services. Underlying the analysis are issues of power -- information, justice and advocacy.
- Critical Issues for the 1990s — having a home and family life, learning and working, making sense of the world, and being

supported to participate in the community. The report discusses the fact that, for the most part, funds are allocated to the system rather than to people. The system must be based on accountability to the person.

- Empowerment means having control over your life. The issue is how to hold services and systems accountable to individuals with such power.

Americans with Disabilities, Agenda for Change (1991).

This flyer called for a new federal Rehabilitation Act that promotes the social and economic independence of people with disabilities as lifelong members of the community. It was part of a nationwide effort to reform the Rehabilitation Act and establish four value-based policy foundations in legislation:

- Career Development First
- Personal Empowerment and Build Community
- Youth as a Priority
- Life Long, Sustainable Technology and Personal Assistance.

A New Way of Thinking (1987).

This briefing book for policymakers and many others who are interested in systems change focused on new ways of thinking (paradigm shifts) about basic issues important to the quality of our lives:

- a real home to live the most personal moments of our lives;
- a real education that is lifelong and useful to our lives and careers;
- real work that involves earning a living, being productive and making a contribution to our community; and
- developing and sustaining relationships -- having real friends at the core of our lives, people who are involved because they want to be, not because they are paid to be.

A companion videotape was also developed. In total, 50,000 copies of A New Way of Thinking have been distributed. This briefing booklet has been translated into several languages and seen by many as a "break through" document. People carried it with them to meetings. Conferences were organized around it. The videotape won awards.

Mandate for Action: Recommendations of the Governor's Mental Health Commission (February 3, 1986).

In 1985, Governor Rudy Perpich was preparing a speech for the Range Mental Health Center. Two advocates met with the Governor's speech writer and suggested that a Blue Ribbon panel was needed to look at the mental health system. Governor Perpich announced The Governor's Commission on Mental Health. On June 14, 1985, the Commission was appointed to look at several aspects of mental illness and issues related to mental health services and policy. The State Planning Agency, specifically the staff of the Governor's Council on Developmental Disabilities, was called upon to provide technical assistance and staff support to the Commission.

While some positive trends and exemplary services were highlighted, one sentence in the Commission's report was widely quoted:

In other words, the "system" is, to a significant extent, divided, inconsistent, uncoordinated, undirected, unaccountable, and without a unified direction. (Page 10)

Recommendations were organized according to three themes: making a commitment, organizing to meet the commitment, and ensuring that the commitment was met.

Over two subsequent Legislative Sessions, major reform of the mental health system began. *Serving Minnesota's Mentally Ill: An Introduction* by the League of Women Voters of Minnesota Education Fund (1988)(page 6) chronicles the developments after the release of the report:

In February 1986, the Program Evaluation Division of the Legislative Auditor's Office released a study on the coordination of care for people discharged from the state regional treatment centers (formerly state hospitals) to the community. The report found that significant numbers of persons were released... without adequate discharge plans and community follow-up and were soon rehospitalized.

In March 1986 the Public Citizen Health Research Group ranked Minnesota 37th among the states in its program for the care and treatment of persons with serious and persistent mental

illness.

In response to these reports, the 1986 Legislature introduced and enacted (Minn. Stat. 245.69) a mission statement for Minnesota's mental health system beginning: "The Commissioner of Human Services shall create and ensure a unified, accountable, comprehensive system of mental health services."

... In 1987, the Minnesota Legislature passed the Comprehensive Mental Health Act ... requiring all 87 counties to provide a continuum of specific services for persons with mental illness, some local and some on a regional basis.

Testimony of Colleen Wieck: Needed Changes in the Medicaid System, and Support for the Community and Family Living Amendments (1986).

Efforts to change the direction of Medicaid -- in support of community living and families -- drove the policy work of the Council for over a decade.

In April 1986, on behalf of the Minnesota Governor's Council, Colleen Wieck testified to Senator John Chafee and the Community and Family Living Amendments Forum in Chicago, Illinois. The testimony summarizes the results of a nine-month study of the state hospital system (see Policy Analysis Series: Issues Related to Minnesota's State Hospitals).

In September 1986, Colleen Wieck testified to the Senate Finance Committee about needed changes in the Medicaid program. The testimony is divided into four parts:

- Billions of dollars are spent, but what are the outcomes? Medicaid may foster "retarding environments" and "inactive treatment".
- Medicaid is a powerful incentive for out-of-home placements.
- Restructuring Medicaid means tough issues, inevitable choices and political heat.
- Restructuring Medicaid means catching the new waves and funding what is needed, and what is possible.

Early Intervention: You can make the difference! (1985).

This poster was issued by the Minnesota Department of Education, Division of Special Education. It supported the development of early intervention services for all children with disabilities from birth to three years. It called on school boards to enter into cooperative ventures with other services to ensure that early intervention programs would be available in all parts of Minnesota.

Toward a Developmental Disabilities Policy Agenda: Assuring Futures of Quality (March 1984).

This publication stressed that people with disabilities should live, learn, work, and participate with other citizens without disabilities. It identified the following essential components — a statewide prevention and early intervention system, family support services, an education which would prepare students for independent living, community integration and opportunities for competitive employment, an array of community residential alternatives which would be flexible and responsive to individual needs, and access to technology which could improve the quality of life for persons with developmental disabilities.

...Assuring Futures of Quality identified what was currently happening in the State, what we knew to be possible, and a goal for the future. It articulated a vision of the future — supporting communities to act responsibly, to be competent, to recognize and support the citizenship of Minnesotans with developmental disabilities. It articulated a description of what a community would be like when it is responsive to people with disabilities.

...Assuring Futures of Quality began the process of switching the question away from incentives, slots and arrays of services to developing the capacity of communities and promoting inclusion.

Fiscal Disincentives in the Service System for People with Developmental Disabilities (June 1983).

This report examines a set of funding and cost-sharing mechanisms that result in the placement of people with developmental disabilities in the most expensive residential settings even when they could be

served more appropriately with less expensive services. The report describes how adjusting cost-sharing formulas and program funding changes incentives to county governments. In Minnesota, counties are responsible for placement decisions that should not be financially based.

The report was prepared by the Metropolitan Council with funding from the Governor's Council on Developmental Disabilities.

Developmental Disabilities and Public Policy, A Review for Policymakers (January 1983).

This publication provided information about persons with developmental disabilities, trends in community services, and policy issues and alternatives for the 1980s. Support for the policy goal of normalization was recommended, as was movement toward a consumer-powered system.

Funds were originally identified to sponsor several presentations to legislative members. Because of a state budget deficit, those sessions were not possible. The need was still there — legislators needed a policy orientation to issues facing people with developmental disabilities.

What emerged was the first in a series of policy briefing books for policymakers. The idea was to create an inviting booklet that was accessible, attractive, and delivered the ideas. A photojournalist was hired to create strong visual images. Destiny 2 was hired to develop an attractive package. The Center for Educational Policy Studies prepared the text and brought in a writer to pull together the ideas.

In a review of ten exemplary human service planning efforts, Urban Systems Research & Engineering, Inc. described the marketing strategy:

Like the policy papers, this document was widely disseminated, but in a particularly noteworthy manner. Instead of simply distributing the document by mail, the brochure was personally delivered to key policymakers (e.g., State legislators) by a constituent involved in the developmental disabilities network. There was no concern that, in many instances, legislators received more than one copy.

There was some concern about funding such a presentation, but the costs were comparable to other formats and the impact was higher as a result. Developmental Disabilities and Public Policy created a new standard in publications, especially in comparison to State Plans. It was the style of the message with a clear attempt to capture the imaginations of policymakers. Tens of thousands of copies were distributed, proactively to legislators and reactively to the requests that poured in from across the state and country.

Developmental Disabilities Trends and Services in the Twin Cities Metropolitan Area, The Second Report (December 1980).

This report from the Developmental Disabilities Task Force of the Metropolitan Health Board/Metropolitan Council examines changes which took place in the field of developmental disabilities during the 1970s and the impact those changes might have in the 1980s. It describes the characteristics of people with developmental disabilities in the Twin Cities Metropolitan Area who were receiving services at the time. It provides a regional perspective of the strengths and weaknesses of the existing service network.

Participation of Minorities in the Developmental Disabilities Movement in the Twin Cities Metropolitan Area, An Assessment (February 1979).

This special study was conducted by the Committee on Minority Participation of the Metropolitan Health Board's Developmental Disabilities Task Force during 1978. The study had two purposes. The first was to assess the level of minority employment and participation on boards and advisory committees in the developmental disabilities movement in the Metropolitan Region. The second was to suggest ways for initiating and/or increasing the quantity and quality of minority participation in the developmental disabilities movement.

1.2.2 Early Reform Efforts

The Assessment of Disability in Minnesota, A Household Survey. Han Chin Liu, Ph.D. and Eugene R. Perkins, Ed.D. Monograph Number 2, Research and Special Projects Monograph Series, Division of

Vocational Rehabilitation, Minnesota Department of Economic Security (November 1978).

This study was the only one of its kind in Minnesota. The study sampled households in the state and, using a functional assessment approach, estimated the numbers of people with disabilities in Minnesota. The conclusion was that approximately one in seven (14.5%) non-institutionalized Minnesotans was found to have functional disabilities. Physical disabilities accounted for most of the functional limitations.

The project was unique in its time in several ways. It was a multi-agency effort, financially supported by several State departments. It was supported by the advice and encouragement of other agencies. The study gathered data to meet the information needs of those agencies. It was also unique because it was not categorical — it looked at the functional needs of the entire population.

The study was also never replicated. There have been persistent calls for the development of a database linked to such a study, but cost has stood in the way.

CAIR — Community Alternatives and Institutional Reform, Planning Alternatives for the Developmentally Disabled Individual (January 1975).

Following the Presidential mandate for deinstitutionalization and in keeping with the National Developmental Disabilities Advisory Council priority, the Minnesota Developmental Disabilities Program received a grant under P.L. 91-517 to create a process for establishing community alternatives for individuals with developmental disabilities.

The grant supported the Community Alternatives and Institutional Reform (CAIR) Project. The primary objectives of the project were to:

- Integrate the viewpoints of financial/program decisionmakers with those of the groups responsible for the implementation of programs.
- Develop a systematic plan for returning persons with developmental disabilities in state facilities to community settings based on their individuals needs.

The CAIR Project led to the development of 1976 Council goals related to Community Alternatives and Institutional Reform:

- To develop strategies and guidelines for implementing a statewide continuum of community-based residential and supportive services based on the CAIR Report.
- To encourage legislation and agency planning which will improve the quality, extent and scope of services provided in state and private residential facilities.
- To improve statewide programs by funding the development of model programs in areas where deficiencies have been identified.

1974 Governor's Conference on Handicapped Persons: Recommendations Presented to Governor Wendell R. Anderson and The Minnesota State Legislature (1974).

This report was developed by a coalition of over 80 committees, councils, consumer groups, public agencies, commissions and private organizations. More than 3,200 concerned citizens, including citizens with disabilities, gathered at the St. Paul Civic Center on October 9, 1974 to personally articulate their unmet needs to the Governor and state legislators. The Minnesota Coalition of and for Handicapped Persons was designated by the Governor to organize the conference.

The recommendations address early intervention and prevention; the education of children with disabilities; health; environmental barriers; community alternatives and institution reform; rehabilitation and employment; human and legal rights; consumer concerns; and the development of a human resource development policy "which will provide goals, in terms of basic human and social values, to guide the activities of policy makers at all levels of government;" a framework for assessing need; and a framework for coordinating the activities of agencies and governments.

Progress and Promise... a report to the Governor on Minnesota's efforts to combat mental retardation and what remains to be accomplished. Prepared by the Minnesota Mental Retardation Planning Council (December 1967).

Action Speaks Louder... A Plan for Minnesota's Mentally

Retarded [A Pamphlet Summary of the Plan] (1964).

Report to the Governor. A Comprehensive Plan to Combat Mental Retardation in the State of Minnesota. Volume 1. A Philosophy of Progress. Prepared by the Minnesota Mental Retardation Planning Council (April 1966).

Report to the Governor. A Comprehensive Plan to Combat Mental Retardation in the State of Minnesota. Volume II. Array of Services: The Facilities Construction Plan. Prepared by the Minnesota Mental Retardation Planning Council (April 1966).

In July of 1964, federal funds were awarded to Minnesota under P.L. 88-156, enabling the beginning of a process that would last three and one-half years. The Governor appointed the 25 member Minnesota Mental Retardation Planning Council to investigate, deliberate, recommend, and implement action "to remedy the effects of many long years of neglect of the mentally retarded" [people]. The Council was to develop a comprehensive plan "to combat mental retardation." Nine Task Forces and seven Regional Committees were formed to aid the Council's work.

In 1966, the two volume Comprehensive Plan... and a companion brochure, *Action Speaks Louder*, were released. Volume I contained hundreds of recommendations for needed improvements in services. Volume II contained the Council's recommendations concerning regional deployment of services and the facilities needed to house those services. This volume, which was to be revised annually, served as the statewide construction plan required under P.L. 88-164 in order to qualify for federal matching funds for construction of "mental retardation facilities."

Progress and Promise... describes what happened over the first year after the release of *A Comprehensive Plan*.

The language of the recommendations summarized in *Action Speaks Louder* is repeated in much of what is written today, though with quite different meaning. In 1964, the ultimate goal was prevention of mental retardation. Today, we place much greater emphasis on preventing the impact of disabilities. The 1964 recommendations contained phrases which resonate today — learning to live; the dignity

of work; a house must be a home... At the time, the meaning of such terms was more in terms of smaller, though still congregated and segregated, programs. The emphasis was on the reform of institutional services, not their elimination.

There were also calls for the employment of people with developmental disabilities in government departments and recognition of the fact that "all other avenues for maintenance in the community" should be pursued before deciding on residential placement. The report contended that "only about five per cent of the retarded [people] actually need residential placement."

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1.2.1 The Agenda for Change — 1980 to today

Minnesotans Speak Out! (1992).

1990 Report: "The heart of community is inclusion..." (1990).

Americans with Disabilities, Agenda for Change (1991).

A New Way of Thinking (1987).

Mandate for Action: Recommendations of the Governor's Mental Health Commission (February 3, 1986).

Testimony of Colleen Wieck: Needed Changes in the Medicaid System, and Support for the Community and Family Living Amendments (1986).

Early Intervention: You can make the difference! (1985).

Towards a Developmental Disabilities Policy Agenda: Assuring Futures of Quality (March 1984).

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1.2.2 Early Reform Efforts

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Action Speaks Louder... A Plan for Minnesota's Mentally Retarded (A pamphlet summary of the Plan)(1964).

Report to the Governor. A Comprehensive Plan to Combat Mental Retardation in the State of Minnesota. Volume 1. A Philosophy of Progress. Prepared by the Minnesota Mental Retardation Planning Council (April 1966).

Report to the Governor. A Comprehensive Plan to Combat Mental Retardation in the State of Minnesota. Volume II. Array of Services: The Facilities Construction Plan. Prepared by the Minnesota Mental Retardation Planning Council (April 1966).

1.3 Policy Analysis Series (PAS) -- Issues Related to the Welsch Consent Decree

The Welsch Consent Decree was signed in U.S. District Court for the District of Minnesota in September 1980. The Consent Decree required the state of Minnesota to substantially reduce the overall population of persons with mental retardation residing in state hospitals by 1987. Provisions of the Consent Decree also addressed the need for improvement of conditions in state hospitals and the development of community services for persons with mental retardation who were to be discharged from state hospitals.

The Policy Analysis Series presents the findings resulting from various studies conducted by the Governor's Council on Developmental Disabilities under the Minnesota State Planning Agency from 1981 to 1990. These studies focused on several of many issues surrounding the process of deinstitutionalization and the dynamics of systems change.

These documents were important in bringing important information to bear on a change process in a timely fashion. They did not require the long delays involved with journal articles. The importance of the Policy Analysis Series in the development of the Governor's Council on Developmental Disabilities after 1980 is described in *When the Going Gets Tough: Ten Exemplary Human Services Planning Efforts — Final Report* (Prepared by Urban Systems Research & Engineering, Inc for the Office of Program Development, U.S. Office of Health and Human Services. September 1985; pages 3-27 to 3-30).

Here are the words of Bill Benton:

The Governor's Planning Council on Developmental Disabilities is a part of the State Planning Agency. As such, it is independent from the major State agencies responsible for administering direct services to Minnesota's developmentally disabled [sic], enabling the Council to take a cross-cutting perspective that would be impossible with a single service delivery agency.

By all accounts, the Council was a moribund agency as recently as four years ago [1981]. The Council was not influential in either State

government or with the more than 200 agencies which comprised the Minnesota advocacy community. The Executive Director appointed by the Council in 1981 set about changing that image.

The most topical issue at the time of her appointment was State compliance (or lack thereof) with a Court Order for deinstitutionalization. Seizing on the current visibility of this issue, the Council's Executive Director formed an alliance with the person appointed by the Court to monitor compliance.

Though not mandated in any way by the Court Order, the staff of the Developmental Disabilities Planning Council began to produce a series of policy papers [Policy Analysis Series: Issues Related to the Welsch Consent Decree] addressing the key issues involved in the deinstitutionalization debate in Minnesota. These papers, averaging 15 pages in length, were timely and relevant to the issues under discussion.

... In all, 22 policy papers were produced [at that time] by the Council staff and widely circulated. The papers were available both separately and bound in attractive binders for more permanent reference.

The policy papers received a great deal of use and a great deal of praise for being scholarly and readable. They bridged the chasm that had previously existed between research and the policy process.

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The relationship between the Court Monitor and the Council's Executive Director was a mutually beneficial one. The Director and her staff were able to provide the Court Monitor with a series of closely reasoned policy analyses dealing with key aspects of alternatives to institutional care. Conversely, the visibility associated with the dissemination of sound, relevant, and timely policy analysis moved the Council from the periphery to the center of Minnesota's policy process almost overnight.

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Having established its credibility in the policy process, the Council staff paused to consider appropriate next steps. What emerged from this reflection was a three-phase strategy to demonstrably improve the care provided to people with developmentally disabilities in Minnesota.

Proceed to _

- _ Welsch v Noot (The Court Order)
 - _ Welsch v Gardebring (The negotiated settlement)
 - _ Overview of Policy Analysis Series (PAS) - Issues Related to Welsch, Nos. 1-30
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-

Overview of Policy Analysis Series (PAS) - Issues Related to Welsch, Nos. 1-30

PAS No.1 Taxonomy of Issues Surrounding Implementation of the Welsch vs. Noot Consent Decree (March 31, 1981).

This paper outlined the planning issues and problems related to the implementation of the Consent Decree and agency responsibilities for certain mandated activities — (a) planning at each level of government; (b) financing deinstitutionalization, (c) administration, licensing, regulating, and monitoring issues; and (d) planning at the individual level.

PAS No. 2 The Size of Community Residential Facilities: Current Guidelines and Implications for Planning (April 10, 1981; revised August 1981).

This paper addressed the types of alternative community living arrangements (at least to the best of our understanding in the early 1980s), which must be developed by counties within the context of the normalization principle. Twelve conflicting guidelines regarding the size of residential facilities were discussed. Review of literature suggested that size of residential facilities may be an important factor in determining the degree to which normalization has been achieved.

PAS No. 3 Interagency Cooperation: The Underlying Concepts of Trust, Incentives, Barriers, and Forms of Linkage (April 14, 1981; revised 8/24/81).

This paper reviewed both the processes which facilitate and those which discourage interagency cooperation. Available research was summarized regarding the concepts of trust, the differences between cooperation and competition, and barriers to and incentives for cooperation. Interagency cooperation was identified as being essential to the implementation of the Consent Decree.

PAS No. 4 Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems (September 1, 1981).

Based on the results of a multiple regression analysis, this report

suggested that eight variables were statistically significant determinants of per diem rates: (a) staff-to-resident ratios; (b) number of nonambulatory residents; (c) years of operation of residential facility; (d) average age of residents; (e) profit/nonprofit status of facility; (f) facility size; (g) family owned and operated facilities; and (h) licensed capacity.

PAS No. 5 Admissions/Readmissions to State Hospitals September 1, 1980 to May 31, 1981: The Behavior Problem Issue (August 31, 1981).

This report analyzed state hospital admission and readmission reports. About 80 percent of admissions from family homes were for respite services and could have been avoided if respite services were available in the community. Nearly 60 percent of the informal admissions for other than respite care specifically mentioned a lack of appropriate community support services. The report also outlined some essential components for planning of community services.

PAS No. 6 The Financial Status of Minnesota Developmental Achievement Centers: 1980 -1982 (January 11, 1982).

Data from all 108 developmental achievement centers were analyzed in terms of revenue, expenditures, profit/loss, program per diems, transportation costs, capital assets, building accessibility, licensed capacity, and daily attendance.

PAS No. 7 The Program Status of Minnesota Developmental Achievement Centers: 1980 -1982(January 18, 1982).

This study of all developmental achievement centers in Minnesota in 1981 focused on personnel and other management issues.

PAS No. 8 The Client Status of Minnesota Developmental Achievement Centers: 1980 - 1982 (January 26, 1982).

The report summarized the general characteristics about clients served by the developmental achievement centers in Minnesota from 1980 through 1982.

PAS No. 9 Summary of Issues, Programs and Clients in Minnesota Developmental Achievement Centers: 1980 - 1982 (February 10,

1982).

This report summarized some of the implications of the survey reports in the Policy Analysis Series Papers No. 6,7, and 8. Problems identified were future staffing levels, support services, client movement, and cutbacks in programs or services. Possible solutions... planning, improved coordination between agencies, refocusing of financial resources, and creation of a viable case management system.

PAS No. 10 An Update to Policy Analysis Series No. 5,
Admissions/Readmissions to State Hospitals June 1, 1981 to
December 31, 1981: The Behavior Problem Issue (April 9, 1982).

This study added further verification to the premise that behavior problems were the major reason for admissions and readmissions of persons with developmental disabilities to state hospitals. Another major reason was the provision of respite care services intended to provide relief to parents and other caregivers.

PAS No. 11 An Analysis of Minnesota Property Values of Community
Intermediate Care Facilities for Mentally Retarded (ICF-MRs)
(July 1, 1982).

This paper dealt with the reality of property values of homes in neighborhoods that contain a group home for persons with developmental disabilities. The findings of this study were consistent with findings of similar research conducted in other parts of the United States — neither changes in property values nor the number or timing of property transactions were related to the presence of a group home.

PAS No. 12 Analysis of Nonformal Training for Personnel Working in the
Field of Developmental Disabilities in Minnesota: 1981-1982
(January 3, 1983).

This study documented the quantity and content of nonformal training events (such as conferences, workshops, and in-service training) that occurred in Minnesota over a two-year period.

PAS No. 13 A Survey of Formal Training Programs in Developmental
Disabilities in Postsecondary Schools in Minnesota and
Adjacent States (January 3, 1983).

This paper summarized the findings of a survey of institutions of higher learning in Minnesota and neighboring states. This study also documented that the distribution of educational resources was uneven throughout Minnesota.

PAS No. 14 Training Needs as Perceived by Residential and Day Program Administrators and Staff (April 13, 1983).

This paper summarized the findings of a survey of residential and day program managers and direct care staff who work in community facilities serving persons with developmental disabilities.

PAS No. 15 An Update to Policy Analysis Series No. 4: Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems: 1980 (March 14, 1983).

This analysis used data from 1980 and was an update to the earlier cost-function analysis reported in Paper No. 4. The study of costs was seen as important for several reasons: (a) the mandate under the Welsch Consent Decree to reduce the number of people with mental retardation living in state hospitals; (b) the continued increase in the number of community-based ICFs-MR; (c) the "double-funding" dilemma of maintaining both a state hospital system and a community-based system of services; and (d) the emergence of alternative, cost-efficient models of residential care such as specialized adult foster care, semi-independent living services, and family subsidy and support programs.

PAS No. 16 A Statewide Summary of Sheltered Employment Programs (April 19, 1983).

This paper presented findings of a survey of 25 sheltered workshops throughout Minnesota during federal fiscal years 1980-1983. The components studied were vocational evaluation, work adjustment training, long-term sheltered work, skill training, work activity, and competitive work.

PAS No. 17 An Update to Policy Analysis Series No. 6 through 9 - The Financial, Client and Program Status of Minnesota Developmental Achievement Centers: 1982 (March 28, 1983).

This paper presented findings of the 1982 survey of 107 Developmental Achievement Centers (DACs) in Minnesota.

PAS No. 18 The Minnesota Family Subsidy Program: Its Effects on Families with a Developmentally Disabled Child (May 2, 1983).

Beginning in 1976, this subsidy program provided grants to families of up to \$250 per month per family to purchase support services. Priority was given to families with children with severe and multiple disabilities.

PAS No. 19 An Update to Policy Analysis Series No. 4 and 15: Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems: 1981 (August 15, 1983).

This paper presented the findings of a study of Minnesota community-based ICF-MR per diem costs. The study used 1981 data to identify factors that could explain differences in per diem rates among ICF-MR facilities. The research showed that the importance of certain variables changed from previous years; however, the issues raised in Paper No. 15 remained relevant.

PAS No. 20 Respite Care: A Supportive and Preventive Service for Families (October 18, 1983).

This paper summarized literature relating to respite care and identified available resources which Minnesota could draw upon when planning and implementing future support services to families.

PAS No. 21 Summary and Analysis of Minnesota Developmental Disabilities Respite Care Demonstration Projects (Federal Fiscal Years 1981-1983) (October 24, 1983).

This continuation of Paper No. 20 presented a summary and analysis of 16 respite care demonstration projects funded by the Minnesota Governor's Planning Council on Developmental Disabilities over a three-year period.

PAS No. 22 Improving the Quality of Life for People with Disabilities: Potential Uses of Technology (April 1984).

This paper summarized literature relating to the expanding utilization of technology for persons with developmental disabilities. The paper recommended the development and implementation of a state policy agenda for use of technology by people with disabilities in Minnesota.

PAS No. 23 An Update to Policy Analysis Series No. 6 - 9 and 17: The Financial, Client and Program Status of Minnesota Developmental Achievement Centers: 1980 - 1984 (January 2, 1987).

This paper examined the data and trends in the provision of services for persons in Developmental Achievement Centers based on survey data from 1980-1984.

PAS No. 24 Minnesota Case Management Study/Executive Summary (February 1988).

Rule 185, first promulgated by the Minnesota Department of Human Services in 1977, was revised in 1981 and 1987. This rule establishes that the individual counties of Minnesota are responsible for the provision of case management services to all persons with developmental disabilities who reside in that county. The Council identified serious problems in case management, wanted to assess the extent and nature of the problem, and develop a policy paper on the issue. This report summarized a study funded by the Council and conducted by the Minnesota University Affiliated Program on Persons with Developmental Disabilities. The study concluded with recommendations to improve case management services.

PAS No. 25 Minnesota Developmental Achievement Centers: An Update to Welsch Policy Analysis Papers No. 6 - 9, 17, and 23 (February 1988).

This paper updated the data and trends in the provision of services for persons in Developmental Achievement Centers based on data from the 1985 survey.

PAS No. 26 Supported Employment: Review of Literature (March 31, 1989).

This paper briefly summarized a review of the literature on supported employment and is a companion piece to Paper No. 27. The literature review explored definitions of supported employment, various

approaches, and barriers.

PAS No. 27 Supported Employment: Review of Grant Recipients and 1986 DAC Data (March 31, 1989).

In 1984, 1985, and 1986, the Council issued Requests for Proposals (RFPs) to cover the priority area of supported employment. The purpose of these grants was to educate providers, parents, and others about supported employment, as well as to establish supported employment positions for persons with developmental disabilities. In 1984, there were five grants with 113 persons placed in community jobs. By 1986, a total of 12 grants resulted in 469 persons placed in community jobs. In the summer of 1987, another survey of training and habilitation services addressed 10 research questions related to community vocational activities.

PAS No. 28 Minnesota Developmental Achievement Centers: 1987 Survey Results (May 1989).

This paper updated the data and trends in the provision of services for persons in Developmental Achievement Centers based on the 1987 survey data.

PAS No. 29 Minnesota Day Training and Habilitation Services: 1988 Survey Results (December 1989).

This paper updated the data and trends in the provision of services for persons in Developmental Achievement Centers based on the 1988 survey data.

PAS No. 30 Financing of Supported Employment for Persons with Severe Disabilities (January 1990).

This study identified various approaches or strategies for financing supported employment. After discussions with individuals in Minnesota and elsewhere, a review of supported employment efforts in selected states, a review of the existing literature, and an exploration of related initiatives in other health and human service areas, several direct and indirect strategies and mechanisms were outlined.

Index by Issue/Subject of Policy Analysis Series (PAS) - Issues Related to Welsch, Nos. 1-30.

Overriding Issues

- _ PAS No.1 Taxonomy of Issues Surrounding Implementation of the Welsch vs. Noot Consent Decree (March 31, 1981).

Interagency Cooperation

- _ PAS No. 3 Interagency Cooperation: The Underlying Concepts of Trust, Incentives, Barriers, and Forms of Linkage (April 14, 1981; revised 8/24/81).

Developmental Achievement Centers/Sheltered Employment/Employment

- _ PAS No. 6 The Financial Status of Minnesota Developmental Achievement Centers: 1980 -1982 (January 11, 1982).
- _ PAS No. 7 The Program Status of Minnesota Developmental Achievement Centers: 1980 -1982 (January 18, 1982).
- _ PAS No. 8 The Client Status of Minnesota Developmental Achievement Centers: 1980 - 1982 (January 26, 1982).
- _ PAS No. 9 Summary of Issues, Programs and Clients in Minnesota Developmental Achievement Centers: 1980 - 1982 (February 10, 1982).
- _ PAS No. 16 A Statewide Summary of Sheltered Employment Programs (April 19, 1983).
- _ PAS No. 17 An Update to Policy Analysis Series No. 6 through 9 - The Financial, Client and Program Status of Minnesota Developmental Achievement Centers: 1982 (March 28, 1983).
- _ PAS No. 23 An Update to Policy Analysis Series No. 6 - 9 and 17: The Financial, Client and Program Status of Minnesota Developmental Achievement Centers: 1980 - 1984 (January 2, 1987).

- _ PAS No. 25 Minnesota Developmental Achievement Centers: An Update to Welsch Policy Analysis Papers No. 6 - 9, 17, and 23 (February 1988).
- _ PAS No. 26 Supported Employment: Review of Literature (March 31, 1989).
- _ PAS No. 27 Supported Employment: Review of Grant Recipients and 1986 DAC Data (March 31, 1989).
- _ PAS No. 28 Minnesota Developmental Achievement Centers: 1987 Survey Results (May 1989).
- _ PAS No. 29 Minnesota Day Training and Habilitation Services: 1988 Survey Results (December 1989).
- _ PAS No. 30 Financing of Supported Employment for Persons with Severe Disabilities (January 1990).

Living Arrangements (Size, Impact on Property Values, Cost Function Analysis)

- _ PAS No. 2 The Size of Community Residential Facilities: Current Guidelines and Implications for Planning (April 10, 1981; revised August 1981).
- _ PAS No. 4 Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems (September 1, 1981).
- _ PAS No. 11 An Analysis of Minnesota Property Values of Community Intermediate Care Facilities for Mentally Retarded (ICF-MRs) (July 1, 1982).
- _ PAS No. 15 An Update to Policy Analysis Series No. 4: Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems: 1980 (March 14, 1983).
- _ PAS No. 19 An Update to Policy Analysis Series No. 4 and 15: Cost Function Analysis of Minnesota Intermediate Care Facilities

for Mentally Retarded (ICF-MR) Per Diems: 1981 (August 15, 1983).

Readmissions to Institutions

_ PAS No. 5 Admissions/Readmissions to State Hospitals September 1, 1980 to May 31, 1981: The Behavior Problem Issue (August 31, 1981).

_ PAS No. 10 An Update to Policy Analysis Series No. 5, Admissions/Readmissions to State Hospitals June 1, 1981 to December 31, 1981: The Behavior Problem Issue (April 9, 1982).

Family Support

_ PAS No. 18 The Minnesota Family Subsidy Program: Its Effects on Families with a Developmentally Disabled Child (May 2, 1983).

_ PAS No. 20 Respite Care: A Supportive and Preventive Service for Families (October 18, 1983).

_ PAS No. 21 Summary and Analysis of Minnesota Developmental Disabilities Respite Care Demonstration Projects (Federal Fiscal Years 1981-1983) (October 24, 1983).

Technology

_ PAS No. 22 Improving the Quality of Life for People with Disabilities: Potential Uses of Technology (April 1984).

Case Management

_ PAS No. 24 Minnesota Case Management Study/Executive Summary (February 1988).

Training

_ PAS No. 12 Analysis of Nonformal Training for Personnel Working in the Field of Developmental Disabilities in Minnesota: 1981-

1982 (January 3, 1983).

_ PAS No. 13 A Survey of Formal Training Programs in Developmental Disabilities in Postsecondary Schools in Minnesota and Adjacent States (January 3, 1983).

_ PAS No. 14 Training Needs as Perceived by Residential and Day Program Administrators and Staff (April 13, 1983).

Index of Policy Analysis Series (PAS) - Issues Related to Welsch, Nos. 1-30

- _ PAS No. 1 Taxonomy of Issues Surrounding Implementation of the Welsch vs. Noot Consent Decree (March 31, 1981).
- _ PAS No. 2 The Size of Community Residential Facilities: Current Guidelines and Implications for Planning (April 10, 1981; revised August 1981).
- _ PAS No. 3 Interagency Cooperation: The Underlying Concepts of Trust, Incentives, Barriers, and Forms of Linkage (April 14, 1981; revised 8/24/81).
- _ PAS No. 4 Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems (September 1, 1981).
- _ PAS No. 5 Admissions/Readmissions to State Hospitals September 1, 1980 to May 31, 1981: The Behavior Problem Issue (August 31, 1981).
- _ PAS No. 6 The Financial Status of Minnesota Developmental Achievement Centers: 1980 -1982 (January 11, 1982).
- _ PAS No. 7 The Program Status of Minnesota Developmental Achievement Centers: 1980 -1982 (January 20, 1982).
- _ PAS No. 8 The Client Status of Minnesota Developmental Achievement Centers: 1980 -1982 (January 26, 1982).
- _ PAS No. 9 Summary of Issues, Programs and Clients in Minnesota Developmental Achievement Centers: 1980 - 1982 (February 10, 1982).
- _ PAS No. 10 An Update to Policy Analysis Series No. 5; Admissions/Readmissions to State Hospitals June 1, 1980 to December 31, 1982: The Behavior Problem Issue (April 9, 1982).
- _ PAS No. 11 An Analysis of Minnesota Property Values of Community Intermediate Care Facilities for Mentally Retarded (ICF-

MRs) (July 1, 1982).

- _ PAS No. 12 Analysis of Nonformal Training for Personnel Working in the Field of Developmental Disabilities in Minnesota: 1981 - 1982 (January 3, 1983).
- _ PAS No. 13 A Survey of Formal Training Programs in Developmental Disabilities in Postsecondary Schools in Minnesota and Adjacent State (January 3, 1983).
- _ PAS No. 14 Training Needs as Perceived by Residential and Day Program Administrators and Staff (April 13, 1983).
- _ PAS No. 15 An Update to Policy Analysis Series No. 4: Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems: 1980 (March 14, 1983).
- _ PAS No. 16 A Statewide Summary of Sheltered Employment Programs (April 19, 1983).
- _ PAS No. 17 An Update to Policy Analysis Series No. 6 through 9 - The Financial, Client and Program Status of Minnesota Developmental Achievement Centers: 1982 (March 28, 1983).
- _ PAS No. 18 The Minnesota Family Subsidy Program: Its Effects on Families with a Developmentally Disabled Child (May 2, 1983).
- _ PAS No. 19 An Update to Policy Analysis Series No. 4 and 15: Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems: 1981 (August 15, 1983).
- _ PAS No. 20 Respite Care: A Supportive and Preventive Service for Families (October 18, 1983).
- _ PAS No. 21 Summary and Analysis of Minnesota Developmental Disabilities Respite Care Demonstration Projects (Federal Fiscal Years 1981-1983) (October 24, 1983).

- _ PAS No. 22 Improving the Quality of Life for People with Disabilities: Potential Uses of Technology (April 1984).
- _ PAS No. 23 An Update to Policy Analysis Series No. 6 - 9 and 17: The Financial, Client and Program Status of Minnesota Developmental Achievement Centers: 1980 - 1984 (January 2, 1987).
- _ PAS No. 24 Minnesota Case Management Study/Executive Summary (February 1988).
- _ PAS No. 25 Minnesota Developmental Achievement Centers: An Update to Welsch Policy Analysis Papers No. 6 - 9, 17, and 23 (February 1988).
- _ PAS No. 26 Supported Employment: Review of Literature (March 31, 1989).
- _ PAS No. 27 Supported Employment: Review of Grant Recipients and 1986 DAC Data (March 31, 1989).
- _ PAS No. 28 Minnesota Developmental Achievement Centers: 1987 Survey Results (May 1989).
- _ PAS No. 29 Minnesota Day Training and Habilitation Services: 1988 Survey Results (December 1989).
- _ PAS No. 30 Financing of Supported Employment for Persons with Severe Disabilities (January 1990).

1.4 Policy Analysis Series (PAS) - Issues Related to Minnesota's State Hospitals

During the 1984 Legislative Session, the Minnesota Legislature mandated the establishment of an Institutional Care and Economic Impact Planning Board to study the feasibility of using state employees in the operation of community-based services and to consider the possible economic effects from consolidation, conversion, or closure of state hospitals. (Minn. Stat., Chapter 654, Section 19). A policy was established that deinstitutionalization be carried out in a manner that ensured protection of the interests of employees and communities affected by the deinstitutionalization of state hospitals.

The Institutional Care and Economic Impact Board consisted of commissioners of the departments of Human Services, Administration, Employee Relations, Health, Finance, Veterans Affairs, Corrections, Economic Security, and Energy and Economic Development, and the Directors of the Housing Finance Agency and State Planning Agency.

The Developmental Disabilities Council, Minnesota State Planning Agency, was given the responsibility for conducting the study and coordinating the plan.

The Institutional Care and Economic Impact Board submitted recommendations and findings to the Legislature on January 31, 1985. The report was contained in eight technical papers, Policy Analysis Services: Issues Related to State Hospitals and an abbreviated policy briefing publication, Minnesota's State Hospitals: Mental Retardation, Mental Illness and Chemical Dependency.

Proceed to _

- _ Overview of Policy Analysis Series (PAS) - Issues Related to State Hospitals, Nos. 1-8 and Minnesota's State Hospitals
- _ Mandate for Action: Recommendations of the Governor's Mental Health Commission (February 3, 1986)

_ Index of Policy Analysis Series (PAS) - Issues Related to
State Hospitals, Nos. 1-8

Overview of Policy Analysis Series (PAS), Issues Related to State Hospitals, Nos. 1-8 and Minnesota's State Hospitals

PAS No. 1 Minnesota State Hospital Facilities and Alternative Use (January 31, 1985).

This study focused on an analysis of the general condition of state hospital buildings and potential alternative uses of those buildings.

PAS No. 2 Minnesota State Hospital Energy Use and Cost (January 31, 1985).

This study compared the use of energy, energy efficiency, and cost for each of the eight state hospitals for the years 1979 through 1983.

PAS No. 3 A Profile of Minnesota State Hospital Employees (January 31, 1985).

This study was directed toward the concern expressed by the Minnesota Legislature as to the effects on the employees should a state hospital close.

PAS No. 4 The Economic Impact of Minnesota State Hospitals (January 31, 1985).

This report analyzed the impacts each state hospital has on the local economy.

PAS No. 5 Public Opinions about State Hospitals (January 31, 1985).

This report summarizes testimony presented at nine town meetings, over 400 letters, and a toll-free call-in day. Citizens were encouraged to provide input regarding the future of state hospitals and the delivery of services to persons with mental illness, mental retardation, and chemical dependency.

PAS No. 6 Residents/Patients in Minnesota State Hospitals (January 31, 1985).

This study focused on the needs of residents with mental retardation and the needs of patients with mental illness or chemical dependency.

PAS No. 7 The Cost of Minnesota State Hospitals (January 31, 1985).

This report was an in-depth review of national literature comparing costs of institutional and community settings for people with mental retardation, the revenue and expenditures of Minnesota's state hospitals, a comparison of community and institutional expenditures during fiscal years 1977 through 1984, and a needs approach to cost estimation.

PAS No. 8 Options and Recommendations for the Minnesota State Hospital System (January 1985).

This report presented several options and a final set of recommendations approved by the Institutional Care and Economic Impact Planning Board.

Options considered in the report were:

- Maintain all state hospitals but reduce staff complement in the mental retardation units and increase staff complements in the mental illness units;
- Decentralize the state hospitals and begin state-operated, community-based services;
- Increase efficiency and introduce elements of competition in all state hospitals; and
- Closure of one or more state hospitals.

Recommendations for the 1985 Legislature included:

- Downsizing the mental retardation units should occur in the 1986-87 biennium with emphasis on natural attrition of staff. Staff ratios should remain in compliance with the Welsch Consent Decree;
- State-operated community services should be developed and tested during the 1986-87 biennium; and
- The efficiency of the current state hospital system should be improved by adding management systems outlined in the section on competition.

Minnesota's State Hospitals - Mental Retardation, Mental Illness, Chemical Dependency (January 31, 1985).

This publication was the executive summary to the Policy Analysis Series: Issues Related to State Hospitals, Policy Papers No. 1 through

7. Changes over two decades are described in terms of reductions in the number of people served by state hospitals, philosophy, and methods of treatment. The report stated that the system had reached a point where decisions were required regarding the types and levels of services offered for people with mental illness, mental retardation, and chemical dependency.

Index of Policy Analysis Series (PAS), Issues Related to State Hospitals, Nos. 1-8

PAS No. 1 Minnesota State Hospital Facilities and Alternative Use (January 31, 1985).

PAS No. 2 Minnesota State Hospital Energy Use and Cost (January 31, 1985).

PAS No. 3 A Profile of Minnesota State Hospital Employees (January 31, 1985).

PAS No. 4 The Economic Impact of Minnesota State Hospitals (January 31, 1985).

PAS No. 5 Public Opinions about State Hospitals (January 31, 1985).

PAS No. 6 Residents/Patients in Minnesota State Hospitals (January 31, 1985).

PAS No. 7 The Cost of Minnesota State Hospitals (January 31, 1985).

PAS No. 8 Options and Recommendations for the Minnesota State Hospital System (January 31, 1985).

Minnesota's State Hospitals - Mental Retardation, Mental Illness, Chemical Dependency (January 31, 1985).

1.5 Minnesota Academies for the Deaf and Blind

In May 1983, the Legislature and the Legislative Audit Commission directed the Program Evaluation Division to study the Minnesota State School for the Deaf, and the Minnesota Braille and Sight-Saving School. Legislators and others wanted to know how the schools had responded to changes in educating people with disabilities and whether the state should continue to provide residential schools for students with hearing and visual impairments.

The report of the Legislative Auditor was prefaced with the following statement:

We have concluded that the residential schools have not made changes in their program and mission that are necessary to better serve students who need the school. We also think the state should carefully reexamine the need to provide residential programs for blind students and the appropriateness of operating a program for multi-handicapped students in the new building that has been constructed on the Braille School campus.

The Executive Summary stated the following about the Minnesota School for the Deaf:

We have concluded that the state should continue to offer the residential school option as part of a full continuum of educational programs for hearing impaired students. We also think that the School for the Deaf needs to make changes in its program and philosophy in order to take its place in a statewide system of services for hearing impaired students.

On January 3, 1985, Governor Perpich made a preliminary recommendation to close the Minnesota School for the Deaf, and the Braille and Sight Saving School. At that time, the State Planning Agency was requested to complete an analysis of the impact this proposal would have on students and submit a report by the end of January 1985. The Governor stated that he would review his decision by mid-February 1985.

By mid-February, after considerable response from many stakeholders, the Governor withdrew his recommendation. In the months following, another

series of evaluations were conducted and working papers prepared about the future of the Academy for the Deaf and the Academy for the Blind. The studies were conducted at the request of the State Legislature and under the direction of Colleen Wieck acting on behalf of the State Planning Agency. Consultants evaluated the two Academies and the Department of Finance reviewed their financial structures. The Department of Administration prepared working papers on Governance Options and Organizational Structure. And finally, the State Board of Education responded to the reports.

Proceed to _

- _ Index of Reports on the Academy for the Blind and the Academy for the Deaf.

Index of Reports on the Minnesota State Academy for the Blind and the Minnesota State Academy for the Deaf .

Study of Minnesota School for the Deaf and Blind. Report Submitted to Governor Rudy Perpich by Minnesota State Planning Agency (1984-1986).

- _ Evaluation of the Minnesota School for the Deaf and the Minnesota Braille and Sight-Saving School. Program Evaluation Division, Office of the Legislative Auditor (January 4, 1984).
- _ The Impact of Closure of the Minnesota School for the Deaf and Minnesota Braille and Sight Saving School from the Perspective of Students, Families, and Local Schools. Minnesota State Planning Agency (February 8, 1985).
- _ Consultant's Report — Minnesota State Academy for the Blind. Fredric Schroeder and David Ticchi (November 18, 1985).
- _ Concise Summary of Recommendations. Fred Schroeder and David Ticchi (November 27, 1985).
- _ The Academic and Residential Programs at the Minnesota State Academy for the Deaf. Frank Zieziula, Ph.D., James Collins, Ph.D., and Gerald Nelson (November 1985).
- _ Financial Structure of the Minnesota Academy for the Deaf and Minnesota Academy for the Blind. Minnesota Department of Finance

(January 1986).

- Working Paper on Governance Options for the Minnesota Academy for the Deaf and Minnesota Academy for the Blind. Management Analysis Division of the Minnesota Department of Administration (January 1986).
- Working Paper on Organizational Options for the Minnesota Academy for the Deaf and Minnesota Academy for the Blind. Management Analysis Division of the Minnesota Department of Administration (January 1986).
- Letter from the Minnesota State Board of Education, Regarding State Board of Education Response on the Consultant Reports Relating to the Faribault Residential Academies. Ruth Myers, President (January 7, 1986).

1.6 Technology

With support from the McKnight Foundation, the Governor's Council on Developmental Disabilities did some research and training on the role of technology in improving the lives of people with disabilities. Policy Analysis Series Paper No. 22 (1984) focused on the potential of technology to improve the lives of people with disabilities. The Council was aware that the issue was important, but there was no funding stream or program at the Federal or State level. In addition to the research that led to Paper No. 22, the Council provided scholarship funds for the 1994 Closing the Gap Conference.

In 1985, Colleen Wieck joined with Linda Carrol (Office of the Minnesota Senate Majority Leader), Michelle Casey (Minnesota Department of Health), and Sharon Patten (University of Minnesota) in presenting a paper on initiating state policy agendas for adapting technology at the Sixth Annual National Conference of the Young Adult Institute. The paper described the background research necessary to assemble a policy agenda, discussed the funding that might be available under Medicaid and a new Congressional bill, and demonstrated the role of the state legislative process in transmitting ideas into action. Colleen Wieck and Lyle Wray also presented a paper at the Conference on a similar topic related to technology.

In October 1985, Governor Rudy Perpich hosted a conference. At that conference, he announced a 19-member Issue Team on Technology for People with Disabilities. The Issue Team was created to investigate the potential of technology to improve the quality of life for Minnesotans with disabilities. The Governor said,

I am convinced that thousands of Minnesotans with disabilities could have their lives greatly improved by technologies which currently exist or by technologies which we have the capability of developing. It is our moral and economic responsibility to do all that we can to get it to them.

The Issue Team explored ways to increase awareness for users, the public and professionals; provide access to appropriate technology-based products and services; and fund research and development that addressed the critical needs in the field. A report was prepared that summarized

their findings and presented their recommendations for strategic action.

The Issue Team's report was presented as a publication that would attract attention and cause action.

Proceed to _

- _ D i s abilities and Technology, Governor's Report on Technology for People with Disabilities (and Executive Summary) (June 1986).
- _ Adapting Technology to Serve the Needs of People with Handicapping Conditions: Strategies for Fostering Change. Lyle Wray and Colleen Wieck. Paper presented to the Sixth Annual National Conference of the Young Adult Institute, New York City, April 24-25, 1985.

Initiating State Policy Agendas for Adapting Technology for People with Disabilities. Linda Carrol, Michelle Casey, Sharon Patten, and Colleen Wieck. Paper presented to the Sixth Annual National Conference of the Young Adult Institute, New York City, April 24, 1985.

See Also

- _ PAS No. 22 Improving the Quality of Life for People with Disabilities: Potential Uses of Technology (April 1984).
- _ Summary — McKnight Foundation. Developmental Disabilities Program, Minnesota State Planning Agency, January 1982 - June 1983 (1983).

1.7 Case Management

Minnesota's Rule 185 (Minnesota regulations governing case management standards and county responsibilities) specifies what case management services are to be provided and minimum standards for how to provide them. Rule 185 was first promulgated by the Department of Human Services in 1977, and revised in 1981, 1984, and 1986. The rule gives little indication of how to use case management services to obtain direct services that promote measurable changes in independence, productivity and community integration.

Rule 185 prescribes a traditional case management process. The

Governor's Council on Developmental Disabilities thought that, in theory, case management should support families and adults with developmental disabilities. This support should be as least intrusive as possible, easily accessible, efficient and cost effective. Case management should be rooted in values which enhance individual growth, personal dignity, inclusion in the social nature of humanity, and dedicated to basic human and constitutional rights. Above all else, case management should produce positive change in people's lives.

The Council set out to discover whether these principles applied to case management services in Minnesota. Public testimony indicated that, while case management is one of the most critical services, it was regarded as one of the weakest. The Council focused on case management as its priority for the three year planning cycle 1986-1989. It sought grant applications that addressed research, improving case management, empowering consumers, and volunteer monitoring.

The Minnesota Governor's Council on Developmental Disabilities funded the following projects during that period:

- Minnesota UAP Case Management Study
- Microcomputerized Case Management
- Case Management Team Resource Development
- Personal Futures Planning Training & Resource Development
- Consumer Case Management
- Partnership for Quality Services
- Peer Advocacy

A number of publications resulted from these grants and are summarized below. The Personal Futures Planning work is presented in Theme 2: Advocacy and Empowerment. Other projects are described in various summaries of Grant Projects in Theme 3: The Governor's Council, Section 3.2 Grants Policy and Reports about What Happened.

Proceed to _

- _ Overview of Case Management Reports
- _ Index of Case Management Reports

See Also

- _ Theme 2: Advocacy and Empowerment, Section 2.1 Self Determination and Personal Futures Planning

– Theme 3: The Governor’s Council, Section 3.2 Grant Policy and Reports about What Happened

Overview of Case Management Reports

Shaping Case Management in Minnesota -- in theory, reality and practice. Minnesota Governor’s Planning Council on Developmental Disabilities (January 1991).

In 1991, Rule 185 was again in the process of being revised. Several areas within the rule revision were seen by the Governor’s Council as better connecting theory, reality and practice. These recommended revisions were a result of projects funded, in part or in full, by the Council. Other aspects of the Rule and its delivery required more change.

This document reviews the theory, reality and practice of case management in Minnesota based on the experiences of Case Management Grant recipients from 1986 to 1989. It recommends further changes in case management and broad system changes in the areas of training, the use of community supports, cash payments to families, parents as case managers, more effective means for keeping records and thus freeing staff time for actual case management, citizen monitoring of services, training parents and adults with developmental disabilities to work in partnership with case managers, rewarding creative solutions, and eliminating public guardianship and replacing it with adequately funded private guardianship.

Case Management: Historical, Current and Future Perspectives. Edited by Mary Hubbard Linz, Patricia McAnally, and Colleen Wieck. Cambridge, MA: Brookline Books (1989).

In 1986, a conference was held in Minnesota to address topics in case management for persons with developmental disabilities. The conference was co-sponsored by the Minnesota University Affiliated Program for Persons with Developmental Disabilities and the Minnesota Department of Human Services. Several conference speakers gave permission for their presentations to be published. Then, other experts in the field were asked to contribute chapters for the resulting publication.

Case Management emphasizes major historical, functional and conceptual issues, the life cycle needs of persons with disabilities and their families, the essential importance of organizing the natural strengths of communities, the creative roles of parents and other family members, new and creative case management models, the implications of critical life transitions in early childhood and later adolescence, and important challenges in philosophy, law, regulation, and management practices in providing support through case management. The book is about improving the connections of people, with needed support and services, with their friends and with their communities.

Minnesota Case Management Study. Patricia McAnally and Mary Hubbard Linz. Project Report Number 88-2. Minnesota University Affiliated Program on Developmental Disabilities, University of Minnesota (1988).

The reality faced by many people with developmental disabilities is that they often have multiple needs which a single agency is hard pressed to meet. Thus, they may be receiving services from a variety of agencies and professionals at the same time. These agencies, programs, and professionals often have dissimilar goals, patterns of service delivery, and methods of operation. These factors can result in confusion for the individual; and often create interagency and interprofessional conflict, gaps in services, and sometimes duplication of services.

This study of case management addressed the following questions:

- . What is the current status of case management practices in Minnesota?
- . What barriers impede the effective delivery of case management services?
- . What gaps and duplications exist in the provision of case management services to individuals with developmental disabilities?
- . What programs or program functions of case management services are perceived as effective by clients and/or parents/guardians, providers, and case managers?
- . What factors and strategies contribute to the effective delivery of case management services?
- . What strategies could be used to improve the availability, effectiveness, and coordination of case management services in Minnesota?

The study identified four areas as the most critical to address immediately if services are to become more effective -- training, funding, staff shortages, and evaluation.

The Case Management Team: Building Community Connections. Toni Lippert. Developmental Disabilities Program of the Metropolitan Council (1987). Reprinted by Minnesota Governor's Planning Council on Developmental Disabilities (October 1989).

A grant from the Governor's Planning Council on Developmental Disabilities with matching support from the Metropolitan Council funded this publication. It presents ideas about how families and case managers can use case management to increase the integration of people with developmental disabilities into their community. The booklet proposes that case management can translate the integration philosophy into practice. In many ways, The Case Management Team is a primer on case management and integration for families, case managers, service providers, and advocates.

Index of Case Management Reports

Shaping Case Management in Minnesota -- in theory, reality and practice. Minnesota Governor's Planning Council on Developmental Disabilities (January 1991).

Case Management: Historical, Current and Future Perspectives. Edited by Mary Hubbard Linz, Patricia McAnally, and Colleen Wieck. Cambridge, MA: Brookline Books (1989).

Minnesota Case Management Study. Patricia McAnally and Mary Hubbard Linz. Project Report Number 88-2. Minnesota University Affiliated Program on Developmental Disabilities, University of Minnesota (1988).

The Case Management Team: Building Community Connections. Toni Lippert. Developmental Disabilities Program of the Metropolitan Council (1987). Reprinted by Minnesota Governor's Planning Council on Developmental Disabilities (October 1989).

SEE ALSO POLICY ANALYSIS SERIES (PAS) ON CASE MANAGEMENT

PAS No. 24 Minnesota Case Management Study/Executive Summary

(February 1988).

1.8 Family Support

Supporting families to stay together, rather than fund services which remove children from the family, has been a long term focus of the Council. This orientation is expressed time and again in The Big Picture documents presented in Section 1.2. In addition, the Council has supported a number of papers and efforts linked to creating specific systems change in terms of family support.

Minnesota also was in a position to provide leadership for the nation. Because of the Welsch Consent Decree, Minnesota was the second state to have a family subsidy program. To promote a family support program generally, the Council needed to document the success of the family subsidy program. Policy Analysis Series Paper No. 18, The Minnesota Family Subsidy Program... was one of the first documents of its kind. Other documents from 1984 to 1994 promoted family support initiatives.

Proceed to _

- _ Overview of Family Support Papers
- _ Index of Family Support Papers

SEE ALSO POLICY ANALYSIS SERIES (PAS) ON FAMILY SUPPORT

- _ PAS No. 18 The Minnesota Family Subsidy Program: Its Effects on Families with a Developmentally Disabled Child (May 2, 1983).
- _ PAS No. 20 Respite Care: A Supportive and Preventive Service for Families (October 18, 1983).
- _ PAS No. 21 Summary and Analysis of Minnesota Developmental Disabilities Respite Care Demonstration Projects (Federal Fiscal Years 1981-1983) (October 24, 1983).

See Also Grant Policy and Reports about What Happened — The Voucher System

- _ Dakota County Account Management Program. Humphrey Innovation and Organization Project (June 1, 1992).
 - _ Dakota County Account Management Project (undated).
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Overview of Family Support Papers

Family Support Media Packet. (Prepared to support The Families of Children with Disabilities Support Act). Distributed by Allan Bergman (United Cerebral Palsy Association) and Fran Smith (Consultant) (April 1994).

In 1993 and 1994, families of children with disabilities from all over the United States, together with many national organizations, worked to develop recommendations for federal legislation on family support for children with disabilities. In 1994, the U.S. Senate Subcommittee on Disability Policy, which was part of the full Senate Committee on Labor and Human Resources, planned to introduce federal legislation that advocated for family-centered and family-directed systems of support. The bill was eventually added to the Education Act, but never funded.

The Minnesota Governor's Council on Developmental Disabilities funded a public relations firm to develop a media package that organizations and families could use to educate policymakers about such legislation. The resulting package is an example of an educational tool that outlines the values of family support, and makes a case for family support programs and services. It also presents Minnesota's efforts to both value families and save money.

Family Support -- A Check for Quality. The Family Support Project, The Arc National Headquarters (January 1993).

This publication was supported by a grant from the Minnesota Governor's Council on Developmental Disabilities. In four pages it defines family supports, identifies the goals of family support and how to know when you are receiving quality family supports, and provides tips for working with family support providers. A Family Support Quality Checklist is included and forms the basis for checking quality and advocating for better quality family supports. The checklist was developed by a consensus forum involving consumers, family members, and professionals.

Family Support: Toward a New Policy Agenda, A Study of Community Responsiveness in Preventing Harm to Children with Developmental Disabilities. Paul Kiley, Consultant. Submitted to Developmental Disabilities Program Office, Minnesota State Planning Agency (February

28, 1985).

A statewide conference, "Preventing Harm to Children with Disabilities," was held in Minneapolis in May 1982. Conference participants, including parents and professionals, recognized that each was in a key position to be aware of how violence jeopardizes a family's future. Many people indicated that they had acquired knowledge and skills useful to work or home settings. The 1982 conference identified the following six strategies that could be initiated or further developed in local communities to attain the goal of preventing harm to children with disabilities:

- developing family member support groups...;
- providing or strengthening sex education programs and resources;
- strengthening parenting skills by affording parents consistent educational experiences by providing them with age-specific, disability-specific practical information that addressed the needs of children and families;
- developing respite care/in-home services;
- developing school policies/procedures and service coordination activities that speak to the needs of children with disabilities;
- planning and implementing training for professionals in identifying, responding to, and providing followup services for families jeopardized by violence in their lives.

Family Support.... is a review of what happened in Minnesota communities after the conference to prevent harm to children with disabilities. It reports on three regional workshops and the results of a survey distributed to 400 professionals and parents. The report looks at the goals for prevention outlined in 1982, the current status of community responsiveness to children with disabilities at risk of abuse/neglect, the real possibilities of effective action, and future steps toward the goal of preventing harm to children with disabilities.

The Development of Family Support Programs. Colleen Wieck, Minnesota Governor's Council on Developmental Disabilities (1984).

This paper by Colleen Wieck focuses on definitions of family support; impetus for change, barriers to family care, and future directions. In a biting and humorous approach, the paper presents four major laws and thirteen corollaries patterned after Murphy's Law. The four laws are:

- Human problems tend to be defined in terms that require

professional solutions thus rendering them insoluble (definitions).

- If your child with disabilities only needs 10 minutes of assistance, you can only receive 24 hours of care, and that care is usually out of home (impetus for change).
 - Learning disability is to mental retardation as family support is to welfare (barriers to family care).
 - Family support programs that require no professional training today will soon require certification, accreditation, annual national surveys, federal grants, public service announcements, and a history by Richard Scheerenberger (future directions).
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Family Support Media Packet. (Prepared to support The Families of Children with Disabilities Support Act). Distributed by Allan Bergman (United Cerebral Palsy Association) and Fran Smith (Consultant) (April 1994).

Family Support -- A Check for Quality. The Family Support Project, The Arc National Headquarters (January 1993).

Family Support: Toward a New Policy Agenda, A Study of Community Responsiveness in Preventing Harm to Children with Developmental Disabilities. Paul Kiley, Consultant. Submitted to Developmental Disabilities Program Office, Minnesota State Planning Agency (February 28, 1985).

The Development of Family Support Programs. Colleen Wieck, Minnesota Governor's Planning Council on Developmental Disabilities (1984).

SEE ALSO POLICY ANALYSIS SERIES (PAS) ON FAMILY SUPPORT

PAS No. 18 The Minnesota Family Subsidy Program: Its Effects on Families with a Developmentally Disabled Child (May 2, 1983).

PAS No. 20 Respite Care: A Supportive and Preventive Service for Families (October 18, 1983).

PAS No. 21 Summary and Analysis of Minnesota Developmental

Disabilities Respite Care Demonstration Projects (Federal Fiscal Years 1981-1983) (October 24, 1983).

1.9 Employment

In the early and mid-1980s, the Minnesota Governor's Council on Developmental Disabilities, through its grant program and the McKnight Foundation, supported a number of initiatives related to supported employment. These projects developed a body of local examples of supported employment at work, began to identify implementation issues, and established credibility for the concept. In 1985, the U.S. Office of Special Education and Rehabilitative Services (OSERS) approved a five year grant which resulted in the establishment of the Minnesota Supported Employment Project (MnSEP).

These developments created the context for systems change. Policy change was needed to support a more comprehensive approach to supported employment. A new direction usually requires some kind of task force or commission before legislation can be developed. In this case, a task force on employment was the vehicle for change. This method has also been used to support new approaches to delivering services in mental health, family support, case management, and so on.

The Minnesota Legislature created the Task Force on Employment to review and make recommendations to the Legislature and affected state departments regarding the following:

- . The role and function of developmental achievement centers, sheltered workshops, and other services providing employment to people with developmental disabilities.
- . Mechanisms for identifying and placing individuals in appropriate services.
- . Current and recommended funding methods.
- . Current regulations and programs standards... and recommendations for uniform standards.
- . Improved ways of providing employment services to all persons with disabilities.
- . The need and scope of demonstration projects to determine how existing funding can be consolidated or unified to expand community-based/supported employment opportunities.

The Task Force was assigned to the Governor's Council on Developmental Disabilities and the Mediation Center facilitated the process.

The Task Force consisted of representatives from rehabilitation facilities, developmental achievement centers, State departments (Education, Human Services, Jobs and Training), County government and social services, legislators, the Governor's Council on Developmental Disabilities, and advocacy organizations.

The following major goals were recommended for Minnesota's supported employment system:

- . The needs of individual persons with disabilities throughout the state should be met, both in terms of flexibility and quality of service;
- . Choice by persons with disabilities should be encouraged and should guide their placement;
- . There is a need for integration, independence and productivity in the community, on an individual basis, unless determined otherwise;
- . The system should have adequate funding; and
- . The system should be consistent, non-duplicative and easy to administer.

It was generally perceived by the members of the Task Force that Minnesota's supported employments system, at the time, did not meet these major goals.

The recommendations of the Task Force, as well as the votes in favor and against various aspects of the recommendations, are presented.

Proceed to _

- _ Final Report, Legislative Task Force on Employment for People Who Are Disabled. Prepared for Minnesota State Planning Agency. Prepared by Mediation Center, St. Paul, Minnesota (February 1, 1988).

SEE ALSO GRANT POLICY AND REPORTS ABOUT WHAT HAPPENED .

- _ It's Working — Minnesota Supported Employment Project (June 1, 1988).
- _ Reports by Employment Related Activities Grant Recipients. Memo to Members of the Governor's Council on Developmental Disabilities (June 30, 1986).

SEE ALSO POLICY ANALYSIS SERIES (PAS) ON SUPPORTED EMPLOYMENT AND

DEVELOPMENTAL ACHIEVEMENT CENTERS .

Supported Employment Series

- _ PAS No. 26 Supported Employment: Review of Literature (March 31, 1989).
- _ PAS No. 27 Supported Employment: Review of Grant Recipients and 1986 DAC Data (March 31, 1989).
- _ PAS No. 28 Minnesota Developmental Achievement Centers: 1987 Survey Results (May 1989).
- _ PAS No. 29 Minnesota Day Training and Habilitation Services: 1988 Survey Results (December 1989).
- _ PAS No. 30 Financing of Supported Employment for Persons with Severe Disabilities (January 1990).

Developmental Achievement Centers Series

- _ PAS No. 6 The Financial Status of Minnesota Developmental Achievement Centers: 1980 -1982 (January 11, 1982).
- _ PAS No. 7 The Program Status of Minnesota Developmental Achievement Centers: 1980 -1982 (January 18, 1982).
- _ PAS No. 8 The Client Status of Minnesota Developmental Achievement Centers: 1980 -1982 (January 26, 1982).
- _ PAS No. 9 Summary of Issues, Programs and Clients in Minnesota Developmental Achievement Centers: 1980 - 1982 (February 10, 1982).
- _ PAS No. 16 A Statewide Summary of Sheltered Employment Programs (April 19, 1983).
- _ PAS No. 17 An Update to Policy Analysis Series No. 6 through 9 - The Financial, Client and Program Status of Minnesota Developmental Achievement Centers: 1982 (March 28, 1983).
- _ PAS No. 23 An Update to Policy Analysis Series No. 6 - 9 and 17: The Financial, Client and Program Status of Minnesota Developmental Achievement Centers: 1980 - 1984 (January 2, 1987).
- _ PAS No. 25 Minnesota Developmental Achievement Centers: An Update to Welsch Policy Analysis Papers No. 6 - 9, 17, and 23 (February 1988).

1.10 Training and Staff Development

In 1978, the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 95-602) required that State Plans include

an assessment of the adequacy of the skill level of professionals and paraprofessionals serving persons with developmental disabilities in the State and the adequacy of the State programs and plans supporting training of such professionals and paraprofessionals in maintaining the quality of services provided to persons with developmental disabilities in the State (42 USC 6009).

This requirement gave rise to three papers in the Policy Analysis Series on Issues Related to *Welsch v. Levine* (Nos. 12-14).

Also in the early 1980s, a grant from the McKnight Foundation to the Minnesota Governor's Council on Developmental Disabilities funded three years of training workshops on:

- management and organizational development — personnel administration, community integration strategies, governance, legal issues, agency automation, strategic planning, community relationships/humanizing human services; and
- direct care issues — individual program plans and behavior management.

About 1800 people attended the management and organizational workshops, and 1100 attended the direct care series over three years.

In 1989, the Governor's Council on Developmental Disabilities took the initiative to produce training manuals in five areas:

- Technological Adaptations to Increase Independence
- Positive Learning: An Alternative to Behavior Management
- Communication for People with Severe Disabilities
- Positioning
- How to Develop an Individual Plan.

These curricula provided state-of-the-art (at least in terms of 1989) information about areas which were critically important to quality services, particularly for people who proved challenging to the service system. The Statewide System for Training Direct Care Service Providers in Community Programs Project was funded by the Minnesota Governor's

Council on Developmental Disabilities through a collaborative effort with the Institute on Community Integration, University of Minnesota.

In 1991, the Minnesota Legislature enacted legislation that directed the State Board of Technical Colleges, with task force assistance, to develop education and training materials for direct care providers, including families, who provide services to persons with developmental disabilities; and created a task force to report on recommendations for needed changes in both pre-service and continuing education programs.

The State Technical College Task Force on Educational Opportunities for Developmental Disabilities Service Providers issued its report in February, 1993. The report's recommendations represent a commitment of the State Technical College Task Force to make the vision of a state-of-the-art training system/practice a reality in Minnesota. They are a critical step towards the design, development, and implementation of such a system, and a long overdue improvement in the quality of services provided to persons with developmental disabilities.

The Task Force's recommendations responded to six major problem areas:

- . There is a need to secure interagency cooperation and collaboration.
- . There is a need to secure adequate funding to sustain a delivery system.
- . There is a need to develop curriculum and training material that emphasize skills and are competency-based.
- . There is a need to effectively disseminate training and education materials and resources.
- . There is a need to develop a process to evaluate education and training materials that is value- and outcome-based.
- . There is a need to include incentives that will address low wage, high turnover, and staff retention problems.

In 1996, a total of 30 Technical College campuses were offering 25 courses with funding provided by the Council. This is a low cost, value-based, regionally delivered strategy that is aimed at improving competencies rather than focusing primarily on certification.

Proceed to _

_ The Training Modules

- _ Positive Learning: An Alternative to Behavior Management. Wade Hitzing, Ph.D. Produced by the Minnesota Governor's Planning

- Council on Developmental Disabilities (undated - 1989).
 - _Communication for People with Severe Disabilities. Jeff Sigafos, Ph.D. and Theresa Mustonen, M.A. Produced by the Minnesota Governor's Planning Council on Developmental Disabilities (undated - 1989).
 - _How to Develop an Individual Plan. Anne Donnellan, Ph.D. and Mary J. Graczyk, M.S. Produced by the Minnesota Governor's Planning Council on Developmental Disabilities (undated - 1989) .
 - _How to Position People with Severe Disabilities. Joan S. Bergman, Ph.D. Produced by the Minnesota Governor's Planning Council on Developmental Disabilities (undated - 1989).
 - _Technological Adaptations to Increase Independence. Robert Stack. Produced by the Minnesota Governor's Planning Council on Developmental Disabilities (undated - 1989).
- _ State Technical College Task Force on Educational Opportunities for Developmental Disabilities Service Providers (February 1, 1993).

SEE ALSO POLICY ANALYSIS SERIES (PAS) ON TRAINING AND STAFF DEVELOPMENT

- _ PAS No. 12 Analysis of Nonformal Training for Personnel Working in the Field of Developmental Disabilities in Minnesota: 1981-1982 (January 3, 1983).
- _ PAS No. 13 A Survey of Formal Training Programs in Developmental Disabilities in Postsecondary Schools in Minnesota and Adjacent States (January 3, 1983).
- _ PAS No. 14 Training Needs as Perceived by Residential and Day Program Administrators and Staff (April 13, 1983).

and other training related documents

- _ Summary, McKnight Foundation. Governor's Planning Council on Developmental Disabilities (April 1988).
- _ Summary — McKnight Foundation. Developmental Disabilities Program, Minnesota State Planning Agency, January 1982 - June 1993 (1983).

Index of Training and Staff Development Documents

The Training Modules

Positive Learning: An Alternative to Behavior Management. Wade Hitzing, Ph.D. Produced by the Minnesota Governor's Planning Council on Developmental Disabilities (undated - 1989).

Communication for People with Severe Disabilities. Jeff Sigafos, Ph.D. and Theresa Mustonen, M.A. Produced by the Minnesota Governor's Planning Council on Developmental Disabilities (undated - 1989).

How to Develop an Individual Plan. Anne Donnellan, Ph.D. and Mary J. Graczyk, M.S. Produced by the Minnesota Governor's Planning Council on Developmental Disabilities (undated - 1989).

How to Position People with Severe Disabilities. Joan S. Bergman, Ph.D.. Produced by the Minnesota Governor's Planning Council on Developmental Disabilities (undated - 1989).

Technological Adaptations to Increase Independence. Robert Stack. Produced by the Minnesota Governor's Planning Council on Developmental Disabilities (undated - 1989).

The State Technical College Task Force

State Technical College Task Force on Educational Opportunities for Developmental Disabilities Service Providers (February 1, 1993).

1.11 Public Information

The purpose of Minnesota's public information feasibility study was to summarize and interpret existing knowledge to form a basis for planning an effective public information program about developmental disabilities in Minnesota.

The study conducted a literature review, analyzed public information programs in other jurisdictions, and surveyed public information and education activities in the eight developmental disabilities planning regions in Minnesota.

Recommendations regarding public information efforts in Minnesota focused on three important goals:

- The developmental disabilities concept.
- The utilization of services.
- Articulated problems and advocated solutions.

The study called for the development of a state public information plan for developmental disabilities, public information plans for each of the eight planning regions, and a mechanism for continued interrelationships between state and regional personnel responsible for public information programming. Within that framework, nine recommendations were made about public information programming.

This document is primarily of historical interest, and reflects a traditional orientation to attitude change through the use of billboards. The study represents an early attempt to develop a planning framework and cooperative action in a public information context.

Proceed to _

- _ Public Information and Developmental Disabilities: A Feasibility Study. Minnesota State Planning Agency, Developmental Disabilities Planning Office (January 1977).

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I. The Council — Mandate and Tools

A. Mandate

The Minnesota Governor's Council on Developmental Disabilities was established in 1971. State Developmental Disabilities Councils are mandated by the Developmental Disabilities Assistance and Bill of Rights Act as passed by the U.S. Congress in 1970 and most recently amended in 1996 (P.L. 104-183).

The current purpose of the DD Act is to assure that individuals with developmental disabilities and their families have access to culturally competent services, supports, and other assistance and opportunities that promote independence, productivity, and integration and inclusion into the community.

In Minnesota, three separate programs are funded under the DD Act — (1) the Minnesota Governor's Council on Developmental Disabilities; (2) the Institute on Community Integration, a University Affiliated Program, at the University of Minnesota; and (3) the Minnesota Disability Law Center (the state's Protection and Advocacy System).

The Minnesota Governor's Council on Developmental Disabilities is comprised of 27 members, including persons with developmental disabilities and their families, who are appointed by the Governor. At least one-half of the members are persons with a developmental disability or a representative of someone who has a developmental disability. Other members represent the principal state agencies responsible for administering federally funded service delivery systems; and local agencies, non-government agencies and private non-profit groups concerned about services for individuals with developmental disabilities.

Under the DD Act, each state designates a state agency to provide support to the Developmental Disabilities Council. The Governor of Minnesota has most recently designated the Minnesota Department of Administration as the agency responsible for providing administrative services for the Minnesota Governor's Council on Developmental Disabilities. The Council has also been located in other state agencies.

Part B of the DD Act, Federal Assistance to State Developmental Disabilities Councils, states that federal funds are made available to states for the following purpose:

- to promote through systemic change, capacity building, and advocacy activities...
- the development of a consumer and family-centered, comprehensive systems, and a coordinated array of culturally competent services, supports and other assistance
- designed to achieve independence, productivity, and integration and inclusion into the community for individuals with developmental disabilities (Sec. 121).

Specifically, the DD Act of 1996 outlines specific responsibilities for the Council in the following areas:

- Systemic change, capacity building, and advocacy activities;
- Examination of priority areas;
- State plan development, implementation and monitoring;
- Outreach to individuals and families;
- Training;
- Supporting communities;
- Interagency collaboration and coordination, including coordination with related councils, committees, and programs;
- Barrier elimination, systems design, and citizen participation; and
- Public education and coalition development, including training in self-advocacy, educating policymakers, and citizen leadership skills (Sec. 124 (c)).

The DD Act requires the Council to develop a state plan . The state plan, which must be approved by the Secretary of the Department of Health and Human Services, provides the basis upon which the Council carries out programs and activities in specific priority areas under Title II, Part B of the Act. In accordance with the Act, the Council is responsible for developing a three-year state plan that describes the quality, extent, and scope of needed services being provided or to be provided to persons with developmental disabilities; to monitoring and evaluating the implementation of the state plan; and reviewing state service plans for persons with developmental disabilities.

Consistent with its mandate, the Council is also an agent for change and an advocate for the improved quality of life of people with developmental disabilities. The specific responsibilities of State Developmental Disabilities Councils only recently included such explicit language about outreach, training, supporting communities, collaboration, barrier elimination, and coalition development. These changes, in part, reflect the example the Minnesota Governor's Council on Developmental Disabilities has provided to the country in these areas over the years.

B. Tools for Action

By itself, a Developmental Disabilities Council has little real power. The plans it develops are basically the Council's plans, not the State's plan; and the policies it adopts are the Council's policies, not those of the legislature. The mission and mandate of the Council, however, are a call to effect fundamental changes. To effect change, the Council employs a number of tools and strategies, many of which are now reflected in the amended federal legislation.

Over the years, a powerful tool of the Council has been its mandate to allocate a majority of its funds to grants that promote systemic change, capacity building and advocacy activities. In Minnesota, the power of grants has been substantially increased by using private sources as well, most notably the McKnight Foundation.

Another major tool for change has been the development of information and publications for policymakers. The policy briefing books developed by the Minnesota Governor's Council on Developmental Disabilities are recognized standard setters in the United States and around the world. The Council has also been instrumental in developing materials which have effected public policy over the years through connections with other organizations and coalitions.

The Council invests heavily in training both professionals and individuals with disabilities and their families. Capacity building through leadership training is a primary focus of the Council.

The following section provides an overview of the grant activities of the Council. The subsequent section on Issues and Outcomes focuses on major issues that the Council has addressed over the years, particularly through

actions directed at policymakers and training strategies.

II. Grants

In 1970 Congress passed Public Law 91-517, the Developmental Disabilities Services and Facilities Construction Act. This legislation authorized the establishment of states were to establish Developmental Disabilities Councils to guide the development and improvement of necessary services, and advocate for the interests of persons with developmental disabilities. The legislation also established formula grants which were allocated to each state contingent upon the Council preparing and submitting a state plan directed at identifying and meeting the needs of persons with developmental disabilities. The funds were to be allocated and directed toward:

- planning, service demonstration/provision, facility construction/operation that supports the improvement of institutional programs and fosters alternative programs in community settings;
- undertaking advocacy efforts directed at assuring that the rights of persons having a developmental disability are recognized and upheld;
- improving the quality, scope and extent of services available within each state;
- supplementing, not supplanting, existing resource allocations; and
- complementing, not duplicating the provision of services and facilities.

Part of each state's allocation was to be available to other public or private nonprofit agencies, institutions and organizations for the purpose of fulfilling these responsibilities. The Developmental Disabilities allocation was to comprise 70% of a state's total program, with the remaining 30% to come from state and local resources.

In 1975, Congress passed P.L. 94-103, the Developmental Disabilities Assistance and Bill of Rights Act, which extended and revised the 1970 legislation. The 1975 Act reinforced and expanded the planning and advocacy roles of each state's program. Funding ratios were shifted to 75%/25%, respectively.

Council Grants

Since its inception, the Minnesota Governor's Council on Developmental Disabilities has awarded two types of grants:

- One type was for developing/improving the delivery of services, referred to as "demonstration" or "innovation" grants;
- The second type was for the support of regional Developmental Disabilities programs having a Council arrangement similar to that at the state level. Generally, parallel planning and influencing roles were undertaken by regional councils at the local level.

As part of the process of developing State Plans, the Council selects priority areas every three years and funds projects that are designed to carry out those priorities. An in-depth review for the years from 1980 to 1990, examined the planning, policy development and funding work of the Council. The review analyzed the crucial issues and challenges of the times, and the Council's response and accomplishments. Grant funds at the beginning of the 1980s were used to expand services such as respite care. Attention then focused on improving selected federal priority services such as employment and case management. The Council's concerns then shifted to improving the results and outcomes of the service delivery system, paying special attention to the day-to-day impact that occurred in the lives of individuals with developmental disabilities and their families. Leadership is the most recent priority.

The McKnight Foundation

In December 1981, the McKnight Foundation awarded \$300,000 a year, renewable for up to three years, to the Minnesota Governor's Council on Developmental Disabilities. This grant came at a critical time because of a sizeable State government deficit. The McKnight Foundation grant was a private sector source of funds when government funds were becoming tighter and tighter. The Foundation had been receiving a large number of grant requests and wanted to find a group to handle these spontaneous requests. The Council was asked to re-grant the funds to help address current problems.

Private funding would allow innovation without government guidelines. It created a dynamic research and development capacity within the Governor's Council on Developmental Disabilities.

The McKnight Foundation program focused on different areas over the three year period:

- Training for staff and boards of facilities serving persons with developmental disabilities (all ages);
- Projects that would resolve or mitigate existing problems in delivery of services (Year One). This area was further specified in Years Two and Three as:
 - Projects that would resolve or mitigate existing problems in the delivery of services for persons with developmental disabilities, but not persons with mental retardation (Year Two);
 - Projects what would resolve or mitigate existing problems in delivery of services for persons with developmental disabilities (Years Two and Three);
- Projects that would increase the physical accessibility of facilities providing day services.

McKnight Foundation grants also supported the development and printing of publications and were critical to making Council publications attractive, accessible, and credible in appearance.

III. Issues and Outcomes

In the early 1980s, the Welsch Consent Decree created a context for the work of the Governor's Council on Developmental Disabilities for years to come. The Council focused its attention on issues of deinstitutionalization. A major product of that work was the Policy Analysis Series Related to the Welsch Consent Decree. The Policy Analysis Series created the context for two levels of action — a focus on major systems reform issues (new ways of thinking and Medicaid reform particularly) and a focus on specific issues related to both the quality of services and the capacities of individuals, families, and communities.

A. The Welsch Consent Decree Sets the Direction — Deinstitutionalization

On September 15, 1980, United States District Judge Earl Larson signed a

Consent Decree which would have a major impact on the delivery of services to people with developmental disabilities in Minnesota.

... in the summer of 1972, a lawsuit was started challenging the conditions in six of Minnesota's institutions which had residents who were mentally retarded... Two basic claims were made — that institutionalized mentally retarded persons are constitutionally entitled to habilitation services and that mentally retarded persons are entitled to live in the least restrictive setting... A system-wide Consent Decree was entered on September 15, 1980. By its terms, that Consent Decree will run until 1987. (Granquist 1982, page 1)

Between 1972 and 1980, there were numerous trials and hearings. When the Welsch lawsuit was filed in 1972, six state institutions were involved. The Commissioner of Public Welfare and the Chief Executive Officers of the six institutions were named as defendants. Two attorneys of the Legal Aid Society of Minneapolis asked the court to approve the suit as a class action and grant permission to proceed with trial preparation regarding a subclass of Cambridge State Hospital residents.

In 1974, United States District Court Judge Earl Larson issued his first opinion in the case:

Judge Larson found a constitutional basis for the right to treatment or habilitation as well as a state statutory basis for that right under amendments to the Minnesota Hospitalization and Commitment Act enacted after the lawsuit began. He also found a constitutional basis to plaintiffs' claim that the least restrictive setting should be provided for mentally retarded persons. (Granquist 1982, page 5)

The lack of response from the Minnesota legislature to meet the requirements set out in the order led to subsequent complaints, trials and orders. In December, 1977, a Consent Decree applicable to Cambridge State Hospital was approved. In September, 1980, a Consent Decree was approved that covered all eight state institutions then housing people with developmental disabilities.

A summary of the provisions of the Consent Decree was prepared by Legal

Advocacy for Developmentally Disabled Persons in Minnesota:

The Consent Decree as approved by the Court is a 40 page document which contains many specific provisions. There are, however, three fundamental requirements of the Consent Decree. First, the population of mentally retarded persons in the state institutions must be reduced from the present population of about 2,650 to a population of not more than 1,850 residents by July 1, 1987. Secondly, the existing allocation of staff for mentally retarded residents must not be reduced until staffing standards specified in the Consent Decree have been met. There is no requirement that new positions for mentally retarded units in state hospitals be created. Thirdly, there are provisions providing protection for individual residents' rights with regard to individual habilitation plans, provision of adapted wheelchairs for residents who require them, limitations on the use of restraint and seclusion, and provisions governing the use of major tranquilizers.

The Consent Decree also required the appointment of a Court Monitor. The duties of the Court Monitor were summarized in a Bulletin from the National Association of State Mental Retardation Program Directors (Bulletin No. 80-67, November 18, 1980, page 5):

The duties of the monitor include:

- reviewing the extent to which the defendants have complied with the decree;
- reporting semi-annually to the court on the status of implementation efforts;
- investigating reports of alleged non-compliance;
- informing parties to the suit of the factual basis for any findings of non-compliance;
- conducting evidentiary hearings regarding disputes surrounding implementation of the Decree; and
- recommending to the court any corrective actions he deems appropriate.

Dr. Lyle Wray assumed the office of Court Monitor in November 1980. The relationship between the Court Monitor and the Governor's Council on Developmental Disabilities became an important one.

The Consent Decree created a context for significant changes in Minnesota. Much later, Betty Hubbard presented Colleen Wieck with the award for distinguished service of the Association for Retarded Citizens of St. Paul. She described the choices and strategies that emerged within the Governor's Council on Developmental Disabilities at the time.

... Colleen recognized when she joined the D.D. office in 1981 that the Council had a unique opportunity to influence the course of history for persons with developmental disabilities in Minnesota, not by funding direct service projects, but by facilitating the forward movement of deinstitutionalization, set in motion by the Welsch Consent Decree but slowed by a thicket of competing and often contradictory statutes, rules, traditions and turf. The Council, under Colleen's guidance, set about imposing order on the system by describing it in lucid prose, and making recommendations both rational and implementable for change. In the series of 22 policy analysis papers, Colleen has tackled all the issues relating to the successful development of an array of community choices for persons with developmental disabilities and their families, including creative alternatives for persons currently giving, directing or licensing services, a most impressive body of work.

In 1985, the efforts of the Minnesota Governor's Council on Developmental Disabilities in terms of deinstitutionalization led the Office of Program Development, U. S. Office of Health and Human Services to identify it as one of ten exemplary human services planning efforts in the United States. The context and nature of the Council's efforts are described in *When the Going Gets Tough: Ten Exemplary Human Services Planning Efforts — Final Report* (Prepared by Urban Systems Research & Engineering, Inc for the Office of Program Development, U.S. Office of Health and Human Services, September 1985, pages 3-27 to 3-30).

The Governor's Planning Council on Developmental Disabilities is a part of the State Planning Agency. As such, it is independent from the major State agencies responsible for administering direct services to Minnesota's developmentally disabled, enabling the Council to take a cross-cutting perspective that would be impossible from within a single service delivery agency.

By all accounts, the Council was a moribund agency as recently as [1981]. The Council was not influential in either State government or with the 200+ agencies which comprised the Minnesota advocacy community. The Executive Director appointed by the Council in 1981 set about to change that image.

The most topical issue at the time of her appointment was State compliance (or lack thereof) with a Court Order for deinstitutionalization. Seizing on the currency and visibility of this issue, the Council's Executive Director formed an alliance with the person appointed by the Court to monitor compliance.

Though not mandated in any way by the Court Order, the staff of the Developmental Disabilities Planning Council began to produce a series of policy papers [Policy Analysis Series: Issues Related to the Welsch Consent Decrees] addressing the key issues involved in the deinstitutionalization debate in Minnesota. These papers, averaging 15 pages in length, were timely and relevant to the issues under discussion.

... In all, 22 policy papers were produced [at that time] by the Council staff and widely circulated. The papers were available both separately and bound in attractive binders for more permanent reference.

The policy papers received both a great deal of use and a great deal of praise for being both scholarly and readable. They bridged the chasm that had previously existed between research and the policy process.

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The relationship between the Court Monitor and the Council's Executive Director was a mutually beneficial one. The Director and her staff were able to provide the Court Monitor with a series of closely reasoned policy analyses dealing with key aspects of alternatives to institutional care. Conversely, the visibility associated with the dissemination of sound, relevant, and timely policy analysis moved the Council from the periphery to the

center of Minnesota's policy process almost overnight.

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Having established its credibility in the policy process, the Council staff paused to consider appropriate next steps. What emerged from this reflection was a three-phase strategy to demonstrably improve the care provided to Minnesota's developmentally disabled.

The Governor's Council on Developmental Disabilities was represented on an Interagency Task Force called by Governor Quie to develop a strategic plan and coordinated response to *Welsch v. Noot*. The Task Force involved the State Departments of Education, Health, Economic Security, and Public Welfare; Office of the Attorney General; and the State Planning Agency.

During the 1984 Legislative Session, the Minnesota Legislature mandated the establishment of an Institutional Care and Economic Impact Planning Board (the Board) to study the feasibility of using state employees in the operation of community based services and to consider the possible economic effects from consolidation, conversion, or closure of state hospitals. (Minn. Stat. Chapter 654, Section 19). A policy was established that deinstitutionalization be carried out in a manner that ensured protection of the interests of employees and communities affected by deinstitutionalization.

The Board consisted of the Commissioners of the Departments of Human Services, Administration, Employee Relations, Health, Finance, Veterans Affairs, Corrections, Economic Security, and Energy and Economic Development; and the Directors of the Housing Finance Agency and State Planning Agency.

Based on the credibility of the *Welsch Policy Analysis Series*, The Developmental Disabilities Program, Minnesota State Planning Agency, was given the responsibility for conducting the study and coordinating the plan.

The Board submitted recommendations and findings in a report to the Legislature on January 31, 1985. The report was contained in eight technical papers, *Policy Analysis Services: Issues Related to State Hospitals* and an abbreviated policy briefing publication, *Minnesota's*

State Hospitals: Mental Retardation, Mental Illness and Chemical Dependency.

In 1980, there were 2,600 people with developmental disabilities residing in State Hospitals. By July 1993, as a result of the Welsch Consent Decree and Negotiated Settlement, and the development of community alternatives prompted by the implementation of the Title XIX Home and Community-Based Waiver, a total of 875 individuals with developmental disabilities resided in Regional Treatment Centers (State Hospitals). These actions also resulted in fewer people living in large group residences. For instance, in July 1993, there were 4,206 people living in ICFs/MR in Minnesota, a reduction of 416 individuals from the previous year. Of the nearly 3,000 people who receive home and community-based services, about 55 percent of these individuals previously resided in either an ICF/MR or a regional treatment center.

The Policy Analysis Series related to Welsch and the State Hospital series have been widely praised and emulated across the United States and elsewhere.

- I was fortunate to have recently crossed paths with the Policy Analysis Series... The document accurately and sensitively addresses issues currently of concern to Connecticut's Department of Mental Retardation in the face of litigation and a pending consent decrees involving the Connecticut Association for Retarded Citizens (State of Connecticut, Department of Mental Retardation, March 1982).
- I have just read the five policy analysis papers related to the Welsch v. Noot.... These are the best materials produced anywhere to help state and local officials make practical decisions about community care of persons with severe developmental disabilities. In concise, yet comprehensive, style, these papers describe the issues to be dealt with at each level of government and describe the costs and benefits associated with various responses to these issues. The papers are marvels of clarity and, to the extent they are read by local and state officers, should go far to advance the practicality and wisdom of policy decisions in this area (Professor Bruce Balow, Upper Midwest Regional Resource Center, University of Minnesota, February 1982).
- I would like to thank you for your excellent presentation at our

meeting on October 13.... My primary motive in suggesting the discussion on the policy paper on interagency cooperation was to get the members to ask for continuing discussion sessions on the series. Fortunately it worked... The next important step on my agenda is to get the members to carry back this policy information to the organization or disciplines they represent (Metropolitan Council of the Twin Cities Area, Developmental Disabilities Program, October 1981).

- Thanks much for sending me a copy of your Policy Analysis. I am very impressed with this product and could see it as a most useful tool for your state on a variety of levels. I am often surprised with the commonality of the source of our problems in this business and see much of your work applying to Colorado as well (Developmental Disabilities Council Incorporated, Region 10, Colorado, February 1984).
- A special thanks for sending us the Policy Analysis Series. I compliment you on how nicely researched, organized, informative and well written the articles are -- a most useful tool! (State of Colorado, Division for Developmental Disabilities, February 1984).
- The Governor's Planning Council on Developmental Disabilities in Minnesota is noted for its incisive policy analysis series addressing a variety of issues. This paper on the potential uses of technology is characteristically thorough... ("The Developmental Disabilities Planner," Pennsylvania, January 1985).
- As we complete the final report on the Synthesis of Cost Studies on the Long Term Care of Disabled and Impaired Persons for the Assistant Secretary for Planning and Evaluation/DHHS, I wanted to thank you again for your assistance. Your advice on literature sources and issues affecting cost of care research was very helpful (MACRO Systems, Silver Springs, Maryland, June 1985).
- Rud and I so very much appreciate the set of policy papers that you recently sent us on your study of state hospitals. They provide a wealth of relevant information that we will certainly cite in our work. We are awed by the productivity and contribution that you and the

Council continue to make (Ann Turnbull, University of Kansas, Bureau of Child Research, April 1985).

- We have just received the materials; several Policy Analysis Series and the two other brochures... We find the materials quite to the point of our interest and will no doubt be of good help to our uphill job with the retarded children (Professor Anglada, Centre d'educacion especial, Barcelona Spain).

B. System Reform

When the Going Gets Tough... describes a three phase strategy that emerged after the Policy Analysis Series to improve the supports offered to people with developmental disabilities in Minnesota:

Phase I was designed to be educational, and establish a common understanding of Minnesota's problems and programs. The Council's work involved interviews with virtually everyone with any involvement or interest in policy affecting the developmentally disabled in Minnesota, regardless of their point of view. A synthesis of these perspectives was set forth in *Developmental Disabilities and Public Policy: A Review for Policymakers*, an attractive and highly readable document.

Like the policy papers, this document was widely disseminated but in a particularly noteworthy manner. Instead of simply distributing the document by mail, the brochure was personally delivered to key policy makers (e.g., State legislators) by a constituent involved in the developmental disability network. There was no concern that, in many instances, legislators received more than one copy.

Phase II was designed to identify what courses of action were possible to improve services to Minnesota's developmentally disabled.

The orientation of the Council in this process was three-fold:

- Think big.

- Don't ever say it can't be done.
- Don't ever say it can only be done with more money.

In stark contrast with the functions typically associated with advocacy groups, the Council completed an evaluation of the State's day activity centers which severely criticized the inefficiency of those programs. In addition to demonstrably improving those services, the Council earned a reputation for objective analysis not commonly associated with advocacy groups.

The culmination of Phase II was another attractive publication, *Towards a Developmental Disabilities Policy Agenda: Assuring Futures of Quality*. Again the work of the Council received widespread, personal dissemination and served to move discussion within the State to the next phase.

Phase III of the Council's strategic planning agenda involved leadership in building for the future. Perhaps the clearest example of this leadership role was the Council's designation, by the legislature and Governor, to serve as the staff for an interagency board established to deal with the highly controversial issue of closing and consolidating State hospitals. This work involved an extensive set of public hearings across the State and, again, resulted in a series of issues papers [Policy Analysis Series: *Issues Related to Minnesota State Hospitals*] which formed the basis for both public discussion and the interagency board's deliberations.

(Urban Systems Research & Engineering, 1985)

1. Paradigm Shifts

Educating policymakers, the people who have the power to make the changes needed in the system, has been a relentless pursuit of the Minnesota Governor's Council on Developmental Disabilities. This commitment has given rise to a string of publications that have heralded changes in the ways we think about people with disabilities, services, and communities. The policy papers of the Governor's Council on Developmental Disabilities have not only shaped Minnesota policy, but also the policy of other jurisdictions and the federal government.

These documents have traced developments in Minnesota over the years and articulated the values and perspectives that can inform the future:

- t Developmental Disabilities and Public Policy: A Review for Policy Makers (January 1983).
- t Towards a Developmental Disabilities Policy Agenda: Assuring Futures of Quality (March 1984).
- t A New Way of Thinking (1987).
- t Agenda for Change -- Americans with Disabilities (1991).
- t The heart of community is inclusion (1990 Report) (1990).
- t Minnesotans Speak Out (1992).
- t Shifting Patterns (1992).

The strategy used is to ensure accessible writing and information, and personally distribute the information to policymakers. There has also been a commitment to wider circulation. Copies of these and other publications has been free, at least on a single copy basis. A New Way of Thinking and Shifting Patterns deliver their messages on videotape as well.

- . Just a note to tell you how impressed I was with the book, Developmental Disabilities and Public Policy. It was very clearly written, I understood every paragraph, so I am sure the commissioners will find it helpful and vital. In an effort to contact our County Commissioners and Director of Social Services, I asked to be put on the agenda at a County Board meeting. They asked questions, so I felt they were aware I was there !?! I told them the booklet covered "everything you ever wanted to know about Developmental Disabilities, but didn't know who to ask!" (Parenting Resource Centre, Austin, Minnesota, February 1983).
- I received a copy of Developmental Disabilities and Public Policy... I feel this type of report which addresses the opportunities and resources are vital in making the best use of resources and programs for people (Otter Tail County Dept. of Social Services, Fergus Falls, Minnesota, January 1983).
- Thank you for a copy of Developmental Disabilities and Public Policy... We are finding that the data is accurate and up-to-date, the text is very readable, and the outlook is positive and realistic. It is the best

piece of material on this subject we have seen, so we extend our thanks to all who contributed to its production... I agree with the premise in this publication, that one acts in a constructive way, looking for cost-effective alternatives, prevention and creative innovations, when concerned about costs (Sherburne County Social Services, Becker, Minnesota, February 1993).

- The writing in A New Way of Thinking is beautiful and the messages are some of the most philosophically sound and strong I have encountered in this field. I hope you allow me to share this particular piece with students planning on a career in human services. (Karin Melberg Schweir, Saskatchewan, August 1990).
- A New Way of Thinking is one of my all-time favorite videos, so I am really happy to be able to have it readily available to people here in Connecticut (Connecticut Developmental Disabilities Council, March 1992).
- I have recently received a copy of Friends, A New Way of Thinking and a number of issues of the Futurity. After reviewing the materials, it is obvious you all are leading the way in community integration! ... Thanks so much to your staff for sharing and for doing such a super job (The Midland Association for Retarded Citizens, Texas, April 1992).
- Enclosed is your copy of the videocassette A New Way of Thinking which we have broadcast on our local Public Access television stations. I want to thank you for the use of the video. I feel that it will play a significant role in our efforts to bring more public awareness to the area of special education (Santa Barbara County Special Education Local Planning Area, California, November 1991).
- Dick Weatherman asked me recently if it would be acceptable to put Spanish subtitles on the New Way of Thinking videotape. I told him... to go ahead... The request came from a friend of Dick's in Spain who manages a rather extensive community-based program. It is nice to know that our work enjoys an international following. (Robert Bruininks, Institute on Community Integration, Minneapolis, Minnesota, February 1991).

2. Medicaid Reform and Family Support

The Council's work on deinstitutionalization made it abundantly clear that there were many disincentives to people with developmental disabilities living in the community. The system's funding bias was in the direction of out-of-home placements (in other words, families were not supported to stay together), and placement in congregated, segregated environments. Efforts to change the direction of Medicaid -- in support of community living and families -- drove the policy work of the Council for over a decade.

In April 1986, on behalf of the Minnesota Governor's Planning Council, Colleen Wieck testified before Senator John Chafee and the Community and Family Living Amendments Forum in Chicago, Illinois. Dr. Wieck's testimony summarizes the results of a nine-month study of the state hospital system (see Policy Analysis Series: Issues Related to Minnesota's State Hospitals).

In September 1986, Dr. Wieck testified before the Senate Finance Committee about needed changes in the Medicaid program. The testimony is divided into four parts:

- Billions of dollars are spent, but what are the outcomes? Medicaid may foster "retarding environments" and "inactive treatment".
- Medicaid is a powerful incentive for out-of-home placements.
- Restructuring Medicaid means tough issues, inevitable choices and political heat.
- Restructuring Medicaid means catching the new waves and funding what is needed, and what is possible.

A central theme in the Medicaid reform effort has been support to families. Minnesota was in a position to provide leadership on this topic. Because of the Welsch Consent Decree, Minnesota was the second state to have a family subsidy program. To promote family support programs generally, the Council needed to document the success of the family subsidy program. The Policy Analysis Series Paper No. 18, The Minnesota Family Subsidy Program... was one of the first documents of its kind. A 1985 statewide conference documented the link between family support and preventing harm to children with disabilities (see Family Support:

Toward a New Policy Agenda.... 1985). Other documents from 1984 to 1994 described and promoted family support initiatives.

The Council's focus has been on local demonstration and development and work for national policy change. For instance, the Minnesota Governor's Planning Council on Developmental Disabilities worked with The Arc National Headquarters to develop Family Support — A Check for Quality.

In 1993 and 1994, families of children with disabilities from all over the United States, together with the Consortium of Citizens with Disabilities, worked to develop recommendations for federal legislation on family support for children with disabilities. In 1994, the U.S. Senate Subcommittee on Disability Policy, part of the full Senate Committee on Labor and Human Resources, planned to introduce federal legislation that advocated for family centered and family directed systems of support. The bill was eventually added to the Individuals with Disabilities Education Act (IDEA) but never funded.

The Minnesota Governor's Council on Developmental Disabilities contracted with a public relations firm to develop a legislative package that organizations and families could use to educate policymakers about family support legislation. This package outlines the values of family support, makes a case for family support programs and services, and presents Minnesota's efforts to value families and save money.

C. A Range of Specific Issues Related to Deinstitutionalization

The Welsch Consent Decree gave rise to an urgent need to address many issues in community based services. In a 1982 letter to the Bush Foundation, Colleen Wieck summarized the broad parameters:

The present status of deinstitutionalization in Minnesota can be summarized as follows:

- There are eight state hospitals serving approximately 2,500 residents with mental retardation.
- There are 284 group homes or intermediate care facilities for the mentally retarded (ICF-MRs) serving 4,654 residents with mental retardation. Most of the homes (84%) serve 15 or

fewer people.

- The Department of Public Welfare anticipates 59 new group homes will open in the next two years to serve 497 people...
- By 1987, there should be 850 residents from state hospitals moving into community ICF-MRs. This goal is expressed in the Six-Year Plan..., as well as in a Consent Decree (Welsch v. Noot) signed in 1980 before federal judge Earl Larson.

Of the 497 residents in the new ICF-MRs developed by 1984, only 122 individuals are expected to come from state hospitals. This discrepancy is a major concern because of several reasons:

- . The state will not meet the terms of the Consent Decree if the clientele of the new ICF-MRs will be from parental homes rather than state hospitals.
- . The state uses Medicaid or Title XIX to cover the cost of ICF-MRs and with the current deficit the state should be targeting its resources to reach its goals.
- . If there are major changes in Title XIX, the newer facilities will be in greater jeopardy than the more established facilities.

To complicate matters, residents from ICF-MRs should receive day program services away from home in sheltered workshops or developmental achievement centers. Day programs are in serious funding jeopardy.

The current "big holes" in our system are:

- . Development of ICF-MRs that serve state hospital residents who may be multiply handicapped, have behavior problems or are medically fragile.
- . Day program capacity.
- . Making day program buildings barrier free.

These problems represent both urban and rural Minnesota.

(Wieck to Bush Foundation, 1982)

This analysis led to attention being focused, over subsequent years, on day services, staff training and development, and case management . Each was seen as critically important to the success of deinstitutionalization efforts.

The Council's work on case management soon expanded to broader concerns with the empowerment of individuals with disabilities and their families. Efforts to improve services led to the early identification of fiscal disincentives to community services and the need for Medicaid reform. The Council's involvement with Medicaid reform efforts underscored the need to develop the leadership capacities of individuals with disabilities and family members.

D. Day Services, Then Employment

In the context of the Welsch Policy Analysis Series, the Governor's Council on Developmental Disabilities began a serious look at the status of Developmental Achievement Centers in the State. The Three Year Plan for 1983 identified "Day Services" as the state priority for the next three years. The success of deinstitutionalization depended on appropriate "day programs".

In 1981, the Governor's Council on Developmental Disabilities launched a survey of Minnesota's Developmental Activity Centers (DACs). In various memos, Colleen Wieck explained the context and reasons for the survey:

The purpose of the survey is to gather some general, but important, information about Minnesota's DACs so that we might be better able to influence policy and make wise decisions about allocating scarce resources. As you know, many DACs throughout the State are facing, or have experienced, cuts in their operating budgets. A main objective of the survey is to obtain accurate information about DACs and the populations they serve, and then to communicate that information to decisionmakers, i.e., policymakers and persons who make decisions about budgets. (Wieck to Glumack, 11/12/81)

We are undertaking this study for several reasons:

- Since CSSA, much of the information policymakers (e.g., legislators) need to know is no longer readily available.
- Current and probable budget constraints have (or may have) impacts upon day services to persons with developmental disabilities.
- Changes in day services (hours or program content) will probably

- affect residential services in some way.
- The success or failure of Welsch v. Noot (and deinstitutionalization generally) is closely tied to the availability of appropriate day services.
- Finally, CSSA and county funding of day services raises some important questions regarding state policy (Executive and Legislative intent; State department/agency rules and regulations) and implementation.

At the same time, the Council began to support initiatives related to supported employment. Through its grant program and the McKnight Foundation, several projects produced a body of local examples of supported employment at work, identified implementation issues, and established credibility for the concept. In 1985, the U.S. Office of Special Education and Rehabilitative Services (OSERS) approved a five year grant which resulted in the establishment of the Minnesota Supported Employment Project (MnSEP).

These developments created the context for systems change. New public policy was needed to support a more comprehensive approach to supported employment. This kind of change usually requires some kind of task force or commission before legislation can be developed. In this case, a task force on employment was the vehicle used to create new policy. This approach is similar to the change processes used in areas such as mental health, family support, and case management.

The Minnesota Legislature created the Task Force on Employment to review and make recommendations to the Legislature and affected state departments regarding the following:

- . The role and function of developmental achievement centers, sheltered workshops, and other services providing employment to people who are severely disabled.
- . Mechanisms for identifying and placing clients in appropriate services.
- . Current and recommended funding methods...
- . Current regulations and programs standards... Recommendations for common standards...
- . Improved ways of providing employment services to all disabled persons...
- . The need and scope of demonstration projects to determine how

existing funding can be consolidated or unified to expand community-based/supported employment opportunities...

The Task Force was assigned to the Governor's Council on Developmental Disabilities which hired and the Mediation Center facilitated the process.

The task force consisted of representatives from rehabilitation facilities, developmental achievement centers, State departments (Education, Human Services, Jobs and Training); County government and social services, legislators, the Governor's Council on Developmental Disabilities, and advocacy organizations.

The following major goals were recommended for Minnesota's supported employment system:

- . The needs of individual persons with disabilities throughout the state should be met, both in terms of flexibility and quality of service;
- . Choice by persons with disabilities should be encouraged and should guide their placement;
- . There is a need for integration, independence and productivity in the community, on an individual basis, unless determined otherwise;
- . The system should have adequate funding; and
- . The system should be consistent, non-duplicative and easy to administer.

It was generally perceived by the members of the Task Force that Minnesota's supported employments system, at the time, did not meet these major goals.

The recommendations of the Task Force, as well as the votes in favor and against various aspects of the recommendations, are presented.

E. Training and Staff Development

In 1978, the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 95-602) required State Plans for developmental disabilities to provide for

an assessment of the adequacy of the skill level of professionals and

paraprofessionals serving persons with developmental disabilities in the State and the adequacy of the State programs and plans supporting training of such professionals and paraprofessionals in maintaining the quality of services provided to persons with developmental disabilities in the State (42 USC 6009).

This requirement gave rise to a three part series in the Policy Analysis Series on Issues Related to *Welsch v. Levine* (Nos. 12-14).

Also in the early 1980s, a grant from the McKnight Foundation to the Minnesota Governor's Council on Developmental Disabilities funded three years of training workshops on

- management and organizational development — personnel administration, community integration strategies, governance, legal issues, agency automation, strategic planning, community relationships/humanizing human services.
- direct care issues — individual program plans and behavior management.

About 1800 people attended the management and organizational workshops, and 1100 attended the direct care series over three years.

In 1989, the Governor's Council on Developmental Disabilities took the initiative to produce training manuals in five areas:

- Technological Adaptations to Increase Independence
- Positive Learning: An Alternative to Behavior Management
- Communication for People with Severe Disabilities
- Positioning
- How to Develop an Individual Plan.

These curricula provide state-of-the-art (at least in terms of 1989) information about areas which were critically important to quality services, particularly for people who proved challenging to the service system. The series was funded by the Minnesota Governor's Council on Developmental Disabilities and a grant from the Administration on Developmental Disabilities, entitled "Statewide System for Training Direct Care Service Providers in Community Programs Project) to the Institute on Community Integration, University of Minnesota.

In 1991, the Minnesota Legislature enacted legislation that directed the State Board of Technical Colleges, with task force assistance, to develop

education and training materials for direct care providers, including families, who provide services to persons with developmental disabilities, appointed a Task Force to report on their recommendations for needed changes in both preservice and continuing education programs.

The State Technical College Task Force on Educational Opportunities for Developmental Disabilities Service Providers issued its report in February 1993. The report's recommendations

represent a commitment of the State Technical College Task Force to make the vision of a state-of-the-art training system/practice a reality in Minnesota. They are a critical step towards the design, development, and implementation of such a system, and a long overdue improvement in the quality of services provided to persons with developmental disabilities.

The Task Force's recommendations responded to six major problem areas:

- . There is a need to secure interagency cooperation and collaboration.
- . There is a need to secure adequate funding to sustain a delivery system.
- . There is a need to develop curriculum and training material that emphasize skills and are competency-based.
- . There is a need to effectively disseminate training and education materials and resources.
- . There is a need to develop a process to evaluate education and training materials that is value- and outcome-based.
- . There is a need to include incentives that will address low wage, high turnover, and staff retention problems.

In 1996, a total of 30 Minnesota Technical College campuses offered 25 courses, an effort funded by the Governor's Council on Developmental Disabilities. This is a low cost, value-based, regionally delivered strategy that is aimed at improving competencies rather than focusing primarily on certification.

F. Case Management

Minnesota's Rule 185 (Minnesota regulations governing case management standards and county responsibilities) specifies what case management services are to be provided and minimum standards for how to provide

them. Rule 185 was first promulgated by the Department of Human Services in 1977, and revised in 1981, 1984, and 1986. The rule gives little indication of how to use case management services to obtain direct services that promote measurable changes in independence, productivity and community integration.

Rule 185 prescribes a traditional case management process. The Governor's Council thought that, in theory, case management should support families and adults with developmental disabilities. This support should be as least intrusive as possible, easily accessible, efficient and cost effective. Case management should be rooted in values which enhance individual growth, personal dignity, inclusion in the social nature of humanity, and dedicated to basic human and constitutional rights. Above all else, case management should produce positive change in people's lives.

The Council set out to discover whether these principles applied to case management services in Minnesota. Public testimony indicated that while case management is one of the most critical services, it was regarded as one of the weakest. The Council focused on case management as its priority for the 1986-1989 three-year planning cycle. Grant applications were sought that addressed research, improving case management, empowering consumers, and volunteer monitoring.

The Minnesota Governor's Council on Developmental Disabilities funded the following projects during that period:

- Minnesota UAP Case Management Study
- Microcomputerized Case Management
- Case Management Team Resource Development
- Personal Futures Planning Training & Resource Development
- Consumer Case Management
- Partnership for Quality Services
- Peer Advocacy.

These projects analyzed the deficiencies in the case management system; bolstered the capacities of individuals with disabilities and their families to plan and manage; trained case managers; and by putting much of the paper work onto laptop computers in Dakota County, increased the efficiency of case managers.

G. Personal Futures Planning

In 1986, the Council decided not to use case management funds for case managers. Instead, the Council wanted to invest in people and develop the capacity of individuals with disabilities, their families and friends to be in charge of their own destinies.

Funds were awarded to the Metropolitan Council's Developmental Disabilities Case Management Project. Part of the project focused on personal futures planning — recruiting facilitators, demonstrating skills, bringing people together for a conference, and developing a booklet about personal futures planning for persons with developmental disabilities, their families and friends, case managers, service providers and advocates. Beth Mount and Kay Zwernik developed *It's Never Too Early...* in 1988. The accompanying facilitator's manual *Making Futures Happen...* appeared in 1992.

Personal futures planning is a tool for fostering new ways of thinking about people with developmental disabilities. This planning tool helps groups of people focus on opportunities for people with disabilities to develop personal relationships, have positive roles in community life, increase control of their own lives, and develop the skills and abilities to achieve these goals.

Personal futures planning is not just another technique to be added to the human service industry of fashionable fixes. Through futures planning, people work together for social change for one individual. This requires planners to make a commitment to change the quality of life for that individual.

It's Never Too Early... has been a classic publication. Entire agencies are adopting a personal futures planning approach so there are growing and repeated requests for both publications.

- Re: A Rush Order of Making Futures Happen — It means a lot to me to have this information, as I am participating in a Futures Planning meeting for both of my own children in a week. In addition, I am a waiver case manager in New York, and am extremely excited by the person centered planning process (Parent, July 1992).
- Would you please send me 2 copies of your publication It's Never Too Early, it's Never Too Late regarding personal futures planning. One copy is for my sister who is the mother of an adult with developmental disabilities and one copy is for me who is a family member and teacher in special education. This information will help both of us in our related work (Sheepshead Bay, New York, June 1992).
- It's Never Too Early... is excellent. I would like to share this material with the staff with whom I supervise... Again, the booklet is wonderful and has given me a different perspective on person centered planning (Highland Community Services, Bristol, Virginia, April 1994).
- My role in the ARC organization is to develop and coordinate self-advocacy activities for those participating in our programs. The Futures Planning idea seems a common sense and human approach to empowering persons with developmental disabilities (ARC San Francisco, California, October 1990).

H. Empowerment

A service orientation on case management led to a focus on a number of specific issues of empowerment — parents as case managers and personal futures planning. A number of activities supported by the Council, however, complete a broader picture of empowerment. The Council's broader strategy for supporting the power of individuals with disabilities and their families has included a number of elements:

- n Specific Empowerment Projects — In the 1980s and 1990s, the Governor's Council supported a number of distinct projects, each with its distinct origins, that together represented a consistent thread in the Council's support for the empowerment of individuals with disabilities and their families. These projects are described in Shifting Patterns.

- n Advocacy Tools — publications and resources which individuals and families could use to advance their own issues. The Council's publications, *Making Your Case*, *Read My Lips*, and *Action - This Means War* have been much used tools by advocates across Minnesota and North America.
- n Chances to Speak Out — the Governor's Council on Developmental Disabilities has, over the years, provided a number of opportunities for Minnesotans to speak their minds on issues that are important to them. A prime example of these opportunities is presented in *Minnesotans Speak Out*, the report of a 1992 statewide series of town hall meetings and a toll-free call-in day for Minnesotans to express their thoughts on the current structure under which services are provided.
- n Technology — the Council has long supported the use of various technological advances to empower individuals to make their way in the world, to voice and act on their decisions.
- n Training Individuals and Families to be Partners in Policymaking processes — the Council created *Partners in Policymaking*, a leadership training program which is being replicated in 36 states, the Virgin Islands, and Great Britain.

1. Specific Empowerment Projects

Shifting Patterns, an educational tool for policymakers, describes seven empowerment approaches, examples of which were developed in Minnesota:

- Partners in Policymaking
- Parents as Case Managers
- Personal Futures Planning
- Vouchers
- Youth Leadership
- People First
- Career Vision.

This publication, and an accompany video, emerged when the Administration on Developmental Disabilities, U.S. Department of Health

and Human Services, issued a request for proposals related to educating policymakers in 1990. The Minnesota Governor's Council on Developmental Disabilities responded to the request and successfully competed for the grant.

The goal of the Council's proposal was to promote and strengthen advocacy and empowerment skills of individuals with developmental disabilities and their families, and thereby enable them to influence critical policy decisions. It provided an opportunity to bring together discrete projects in a way that would give a more powerful message about approaches to empowerment. Based on the testimony of those who have seen and used *Shifting Patterns*, the idea worked.

- I recently saw your publication, Shifting Patterns, and was so impressed with it. Your Council has captured the best of recent program initiatives and presented them with imagination and appeal (Gulf Coast Mental Health Center, Mississippi, September 1993).
- I borrowed Shifting Patterns and am sharing it with lots of folks... I'm taking it up to everyone I see -- it's great! Thanks for sharing (Texas Mental Health and Mental Retardation Board, July 1993).
- Thank you for sending me your publication "Shifting Patterns". Your section on youth leadership was of particular interest to me since I have worked with one of the students pictured in this piece. I congratulate you on your commitment to the recognition of individuals for their talents rather than their disabilities. (Kristine Sorensen, Film in the Cities, Saint Paul, Minnesota, April 1993).
- [Shifting Patterns] is a most exciting and attractive publication. Combined with the video tape, it should do a great deal to increase the focus and impact of efforts to improve empowerment aimed at the needs of youth, adults and families (Robert Bruininks, Dean, College of Education, University of Minnesota).
- The Shifting Patterns materials you sent are excellent... the materials should receive the highest ratings on quality and content. The information not only explains how spending and life style patterns are changing, it portrays people with disabilities as responsive competent individuals that are capable of making more decisions than they have been allowed. (Georgia Governor's Council on Developmental Disabilities, May 1993).
- In the midst of all the legislative chaos, your new publication arrived like a breath of fresh air. "Shifting Patterns" is marvelously conceived, imminently readable, and wonderfully executed. You did it again! (federal lobbyist, April 1993).

2. Advocacy Tools

Over the years, the Minnesota Governor's Council has produced or supported the production of three types of tools for advocates. The following are examples:

- General guides for advocacy and social change work — *Making Your Case and Action: This Means War...* are examples.
- Checklists related to specific issues and situations — *Test Your Schools's IQ...* and the *Family Support Checklist* are examples.
- Specific guides to lobby for change on specific issues — *Medical Assistance Program...* and *The Family Support Legislation Packet*.

Efforts have always been to create user-friendly tools. This has involved using such devices as pithy cartoons, short check lists that are to the point and easily translated into scores and numbers for advocacy work, and hand-over-hand instructions for making a point about a particular topic.

These tools have been well used and much appreciated in Minnesota and many other jurisdictions.

- I have received a copy of your publication *Making Your Case*. I found it to be a wonderful collection of information that will personally be useful in my relationship with elected officials (Hammel Green and Abrahamson, Inc. Architecture, Engineering, Interior Design, Minneapolis, Minnesota).
- [re: *Making Your Case*] That information is exactly what is needed for our upcoming legislative training workshop... I strongly believe this publication will be of great benefit to all deaf, hard of hearing and hearing participants (Deaf and Hard of Hearing Division, Department of Human Services, St. Paul, Minnesota, December 1995).
- [re: Read My Lips] I am the Director of Quality Assurance for a large "for profit" organization which operates ICF's-MR in Texas. I would like to share your guide with our quality assurance team and local administrators (Special Services Management, Fort Worth, Texas, December 1992).
- I was so impressed with the two documents you have produced. Would it be possible for you to xerox only the section on "Consumer Empowerment" in the one document and send it to me? I have to do a report to our Council on our projects and that format would be the one

I would like to use as a model for the report (New York Developmental Disabilities Planning Council, Albany, New York, November 1992).

- Arizona's council staff tell us that your council is on the leading edge in consumerism and that "Read My Lips" and "This is War" are mandatory reading. Miriam Podrazik of our DD Council is sending a copy of "Read My Lips" statewide to all key administrators (Arizona Department of Economic Security, Division on Developmental Disabilities, November 1992).
- Last year I received a copy of Read My Lips... and have thoroughly enjoyed it. I operate a residential program for adults with developmental disabilities, providing services for sixty-one individuals. This will be an excellent resource tool for not only by support staff but also the direct care staff... I am very excited about the progress being made in our field where we finally acknowledge that individuals with disabilities not only can express their desires but have the right to do so, and we, as service providers have the responsibility to insure that their wants and needs are fulfilled. (Emory Valley Center, Oak Ridge, Tennessee, February 1994).
- Thank you for sending us copies of your ACTION-THIS MEANS WAR. We will be using them in upcoming training for a peer volunteer network located throughout the state of Nebraska. Your materials will be an excellent resource for our volunteers (Nebraska Department of Education, Division of Rehabilitation Services, Assistive Technology Project, August 1990).
- When you called I didn't thank you effectively for Making Your Case. What a grand piece of work! It's just brilliant (MOUTH, Rochester, New York, January 1995).
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- thank you for the courtesy copy of "Read My Lips, It's My Choice". I have read a number of documents which have references this fine work and, thanks to you, we now have it. I am sure the book will be very valuable in Arizona's effort to provide quality services to the developmentally disabled (Arizona Department of Economic Security, Division of Developmental Disabilities, February 1991).

- Yesterday, I received a large box full of invaluable reading materials. I will try to control my greed and read them slowly enough to enjoy the details while digesting the information. (Community Service Council of Greater Tulsa, Oklahoma, February 1991).

3. Chances to Speak Out

On January 27, 1992, the Deputy Commissioner of the Department of Human Services appointed a study group to "review the current structure under which developmental disabilities services are provided and to review costs." The study group decided to seek input from Minnesotans through a series of town meetings. Because of its long track record in town meetings and public input, the Governor's Council on Developmental Disabilities conducted the meetings and prepared a report. This report summarizes the themes discussed at the town meetings and over the phone during a toll-free, call-in day; and concludes with recommendations from the study group.

The themes discussed are:

- . We have a lot to be proud of, and much remains to be done!
- . Individualization
- . Staffing
- . Leadership and Bureaucracy
- . Inequity of Resources -- Inconsistency in the System
- . Community Programs and Supports.

The Governor's Council on Developmental Disabilities converted the information into a slide show related to the realities of Minnesota and quality assurance issues. People from other states recognize familiar patterns within their systems.

- Each packet I have received from you all has been filled with information that is immediately useful for clients here in Kentucky... I just received your "Speak Out!" and find that it addresses many of the same issues we are struggling with -- I've made copies of it for Protection and Advocacy and the Department of Education personnel dealing with transition issues.... Minnesota has been a leader in the process of change and empowerment of the individual. you also do a wonderful job of presenting the issues in written form (The System of

Intervention, Bowling Green, Kentucky, December 1992).

- Thanks for the copy of *Minnesotans Speak Out!*. it's excellent. I would like to get more copies if possible (Polk County Developmental Achievement Center, Crookston, Minnesota, December 1992).

4. Technology

With support from the McKnight Foundation, the Governor's Council on Developmental Disabilities sponsored research and training on the role of technology in improving the lives of people with disabilities. In 1984, Paper No. 22 in the Policy Analysis Series related to Welsch focused on the potential of technology to improve the lives of people with disabilities. The Council was aware that the issue was important, but there was no funding stream or program at the Federal or State level. In addition to the research that led to the PAS paper, the Council sent Minnesota parents to the Closing the Gap Conference in 1984. Colleen Wieck and Lyle Wray presented a paper on technology to the Sixth Annual National Conference of the Young Adult Institute in 1985.

The Policy Analysis Series paper was an important part of the process that led the Governor to host a conference in 1985. In October 1985, Governor Rudy Perpich announced a 19-member Issue Team on Technology for People with Disabilities. The Issue Team was created to investigate the potential of high technology to improve the quality of life for Minnesotans with disabilities. The Governor said,

I am convinced that thousands of Minnesotans with disabilities could have their lives greatly improved by technologies which currently exist or by technologies which we have the capability of developing. It is our moral and economic responsibility to do all that we can to get it to them.

The Issue Team explored ways to increase awareness for users, the public and professionals; to provide access to appropriate technology-based products and services; and to fund research and development that addressed the critical needs in the field. Their report summarizes their findings and presents their recommendations for strategic action. The

Council developed the Team’s report as a publication that would attract attention.

5. Partners in Policymaking

Partners in Policymaking is an innovative national model of leadership training for parents of young children with developmental disabilities and adults with disabilities. Partners in Policymaking is designed to provide state-of-the-art knowledge about issues related to disability and to develop participant competencies to become effective advocates in influencing policy at all levels of government.

The goal of the program is to teach leadership skills so that Partners graduates are effective partners with policymakers in creating systems change. This partnership symbolizes positive relationships. Documented results show that Partners preserves families, and increases the independence, productivity, integration and inclusion of individuals with disabilities and their families into their communities. Partners graduates become active participants in the policymaking process at local, state and national levels.

The program was developed in 1987 under the leadership of Colleen Wieck, Ph.D., Director of the Minnesota Governor’s Council on Developmental Disabilities, and Ed Skarnulis, Ph.D., Minnesota Department of Human Services. Its original focus was to assist people with disabilities and families to get the best possible services and support. One major impetus for the development of Partners, was the experience of trying to change the direction of Medicaid over a decade. Both Wieck and Skarnulis realized the need to develop the capacity of parents to testify before government committees. That is where the power is, and parents were not appearing.

They realized how important it was to teach parents about what is possible and how to influence public officials. The vision of what is possible had been presented in *Toward a Developmental Disabilities Policy Agenda: Assuring Futures of Quality* (1984) and *A New Way of Thinking* (1987) was in production, but a vehicle was needed to communicate and build on the content, and teach leadership skills.

We are very excited about a new Council funded grant to directly address the need for “young or new leadership” in the field. Partners in

Policymaking is designed to recruit "disaffiliated" parents and self-advocates and provide leadership training over a full year. The training is designed to expose these 35 people to the best national state-of-the-art speakers and to require homework assignments at the local, state, and federal levels. Homework means how to get on the agenda, how to advocate and negotiate, and how to work with policy makers. We are also recruiting public official mentors for each participant... If we do this right, we will be building leadership for the Year 2000.

Colleen Wieck, letter to Jean Elder, Assistant Secretary, Office of Human Development Services, Department of Health and Human Services, Washington DC. April 20, 1987

The Governor's Council on Developmental Disabilities used its federal funding for this model empowerment and self-advocacy education program. In the first five years, the average annual budget was \$100,000. By the end of 1996, the Minnesota Partners in Policymaking program had trained about 325 parents and people with disabilities with impressive results. After 13 classes, ten years of funding, and every sign that the program will continue into its 11th year, Partners in Policymaking has been involved in 77 of Minnesota's 87 counties.

The Governor's Council on Developmental Disabilities has also received several federal grants from the Department of Health and Human Services to assist representatives from other states in establishing Partners in Policymaking programs. In 1989, Partners in Policymaking became part of the World Institute on Disability (WID). In 1990, the Governor's Council on Developmental Disabilities and WID conducted the first Partners in Policymaking National Academy in California; 24 representatives from 12 states participated.

At the 1993 National Academy, 36 states were participating. In 1995, Partners in Policymaking could claim more than 4,000 graduates, each part of a growing national network of community leaders serving on policymaking committees, commissions, and boards at local, state, and national levels. By 1996, 42 states had operated Partners in Policymaking programs, though six had discontinued. Three more states were planning to offer the program, and Partners in Policymaking was operational in Great Britain and the Virgin Islands. Many of the state programs were supported by funds received under the Developmental Disabilities Act. A booklet

entitled Partners in Policymaking Restored Out Independence(1995) contains testimonials from Partners graduates across the United States.

... I've got to tell you all the incredible changes in our lives due to Partners... The biggest change was the day Jenny moved into her own house last July. If it weren't for the guidance from all of you, I'm sure Jenny would have been in an S.L.S. designed for 3 kids as the county was proposing — a "mini group home" as I saw it. Partners gave me the determination, confidence, and bolstered my courage to ask for what I really wanted.

... I remember back to the weekend on school integration we had in Partners. I felt enthusiastic about the concept but hesitant when it came to Jenny. I remember thinking this would be great for most kids - you know, higher functioning kids - but maybe not for Jenny. After all, what would happen if she got mad or frustrated and took a swipe at one of the kids.

Boy, was I wrong. Jenny goes to Hastings Middle School - I know it's not her neighborhood school, but the principal there was just so enthusiastic about having her interested in integration and I felt this compromise was worth it...(Lynn Sansale, Feb 13, 1989)

I. The Mental Health System.

In 1985, Governor Rudy Perpich announced the formation of The Governor's Commission on Mental Health to look at several aspects of mental illness and issues related to mental health services and policy. The State Planning Agency, specifically the staff of the Governor's Council on Developmental Disabilities, was called upon to provide technical assistance and staff support to the Commission.

While some positive trends and exemplary services were highlighted, one sentence in the Commission's report was widely quoted:

In other words, the "system" is, to a significant extent, divided, inconsistent, uncoordinated, undirected, unaccountable, and

without a unified direction. While some information exists about the availability and use of services, very little is known about the bottom line - how effective the system is responding to the needs of the people it is intended to serve and support (Page 10).

Recommendations were organized according to three themes: making a commitment, organizing to meet the commitment, and ensuring that the commitment was met.

Over two subsequent Legislative Sessions, major reform of the mental health system began. *Serving Minnesota's Mentally Ill: An Introduction* by the League of Women Voters of Minnesota Education Fund (1988), page 6 chronicles the developments after the release of the report:

[Following the release of *Mandate for Action*], in February 1986, the Program Evaluation Division of the Legislative Auditor's Office released a study of the coordination of care for people discharged from the state regional treatment centers (formerly state hospitals) to the community. The report found that significant numbers of individuals were released... without adequate discharge plans and community follow-up, and were soon rehospitalized.

In March 1986, the Public Citizen Health Research Group ranked Minnesota 37th among the state in its program for the care and treatment of persons with serious and persistent mental illness.

In response to these reports, the 1986 Minnesota Legislature introduced and enacted (Minn. Stat. 245.69) a mission statement for Minnesota's mental health system beginning:

"The Commissioner of Human Services shall create and ensure a unified accountable, comprehensive system of mental health services."

In 1987, the Minnesota Legislature passed the Comprehensive Mental Health Act ... requiring all 87 counties to provide a continuum of specific services for persons with mental illness, some local and some on a regional basis.

